Decision-Making Capacity:
The Enigmatic Gatekeeper for Patients' Right to Self-Determination

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Dissertation

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— to my grandfather who let me feel like Pippi Langstrumpf —

Preface

This dissertation arises from a research project within the National Research Programme (NRP-67) *End of Life* and is funded by the Swiss National Science Foundation (SNFS). In August 2012, I took up a position on this project as a PhD student at the Institute of Biomedical Ethics and History of Medicine at the University of Zurich, enrolling in the PhD program Biomedical Ethics and Law. As a recently graduated clinical psychologist, knowing little about ethics in general and biomedical ethics in particular, I was curious and enthusiastic to learn more about this emerging interdisciplinary field. Thanks to generous funding from the SNFS, I have had the privilege of spending three years getting to know the field, which I still find complex, puzzling, and fascinating. More specifically, I have investigated and engaged profoundly with the subject of decision-making capacity. This concept so challenged me that I struggle to remember a moment during this three years in which I felt bored or fatigued; on the contrary, the challenge motivated me, and I finally felt success, not necessarily in finding solutions to specific problems but in coming to genuinely understand them. This journey to insight was made possible and fruitful by my amazing supervisors, who believed and trusted in me and gave me the necessary room to develop my own thoughts and ideas. Whenever I felt a need for exchange, they were readily available, providing stimulating inputs and encouraging me to go on. My greatest thanks goes to Manuel Trachsel, Nikola Biller-Andorno, and Egemen Savaskan. Furthermore, I was enormously fortunate to be able to conduct my investigations in the context of a well-structured research project with a solid interdisciplinary basis and in cooperation with important policy stakeholders. Advisory board meetings and consultations and presentation and discussion of the project at the Central Ethics Committee (ZEK) meeting of the Swiss Association of Medical Sciences (SAMS) provided important inputs and built confidence. Many thanks are due to the advisory board members Paul S. Appelbaum, Susanne Brauer, Bernice S. Elger, Julian Mausbach, Mike Martin, Christine Mitchell, Michelle Salathé, Egemen Savaskan, Christian Schwarzenegger, and Armin von Gunten. I am also very grateful to my loyal—unfortunately anonymous—proofreader EM878, who did a great job, disburdened me a lot, and made sure that my articles readily entered the publication process. My dissertation project was an adventurous endeavor, a particular phase in my development and career. Sometimes it made me euphoric and self-confident, and I felt absolutely relaxed. At other times, I felt uncomfortable or unproductive and was very critical, both of myself and of science in

general. Having someone to share all these experiences and struggles was an indispensable privilege, and my deepest thanks goes to my dearest friend Theresa, a courageous "fellow sufferer" who is soon to finish her own thesis. She is a wonderful and incredibly emotionally supportive person, with whom conversation is always stimulating. Finally, I am grateful to my psychoanalyst Peter Passett, whose ear remained constantly open. Lying on the couch three times a week in the middle of the afternoon was a welcome "brain airing".

Contents

1 Introduction

„Can our beloved grandma still decide about her medical treatment?“ So asks a family concerned about their relative's confusions and constantly diminishing memory. „I never want to end up ailing in a nursing home, losing my mind; I'd rather die!“ This was my father, telling me about his registration with an assisted suicide organization. „Is he competent or incompetent?“ For adult protection authorities and the courts, and for physicians who are ultimately mandated to answer it, this question is both a hot issue and a puzzle for clinical ethics. If one's capacity for autonomous conduct or actual self-determination is affected, a highly cherished and essential element of one's self-concept is at stake, perhaps even to the extent where people lose their sense of purpose in life. Moreover, concerns about the well-being of other people arise when a diminished capacity for self-determination prevents them from deciding in their own best interests.

The value afforded to personal autonomy is a particular achievement of the last century and has become a cornerstone of Western society as well as in the field of medicine (Beauchamp & Childress, 2009; Faden & Beauchamp, 1986). Patients are granted a right to self-determination in deciding on their healthcare, and therefore their informed consent to medical treatment is sought ensuring ethically and legally warranted conduct (Faden & Beauchamp, 1986). Respect for the patient's autonomy, however, is not the only moral obligation guiding medical practice. Physicians are equally devoted to patients' welfare, which has traditionally been their first and most important commitment to patients; medicine is about caring and healing, so promoting the well-being of others (Buchanan & Brock, 1989; Faden & Beauchamp, 1986). Both autonomy and beneficence then are central moral principles in medicine. However, in instances for example where a patient forgoes life-saving treatment or requests assisted suicide, autonomy and beneficence start to conflict and a balancing of *prima facie* moral obligations becomes necessary.

There are good reasons to respect my father's intention to end his life when it becomes unbearable for him; he is a competent decision-maker. Although I may hold another opinion or evaluate the situation less pessimistically than he does, I honor his decision because it is a self-determined choice, reflecting his deepest values. Thus, respect for a person's autonomy is given precedence over protection safeguarding their well-being where that individual is deemed competent or able to decide autonomously. As against this, in instances where patients' decision-making capacity is doubted, a tendency emerges

to intervene on paternalistic grounds ensuring their well-being—an experience well known to the abovementioned family in caring for their grandmother (Buchanan & Brock, 1989).

The balancing of autonomy and beneficence in particular instances is therefore inherently related to judgments about a patient's decision-making capacity. It is for this reason that the evaluation of decision-making capacity with regard to treatment decisions is a constant issues in clinical practice and has become an important and challenging research subject, particularly from ethical, psychological, medical, and legal perspectives. Moreover, as I will argue, this relation to moral values proves to be more complex than at first sight and substantially contributes to confusions and conceptual controversies.

Decision-making capacity lies between the descriptive and the normative; it concerns a person's mental abilities and characteristics but is not reducible to the mere description of these faculties, as normative considerations are necessarily involved (Buchanan & Brock, 1989; Faden & Beauchamp, 1986; Grisso & Appelbaum, 1998a). On the basis of these intricate connections, questions arise with regard to unresolved challenges concerning (a) adequate criteria for medical decision-making capacity in terms of mental abilities, (b) the significance of the consequences of a treatment decision or the adequacy of risk-related standards, (c) adequate and feasible assessment procedures and the appropriateness of standardization, and (d) the role and handling of values in decision-making capacity judgments. All of these issues are so closely related that the response to any one of them is likely to have implications for the others.

A comprehensive understanding of the concept of medical decision-making capacity is important and requires different angles of approach that may ultimately support more integrative conclusions. The present thesis pursues this integration as an overarching goal. To this end, a cumulative approach has been adopted, drawing on multiple contributions on specific issues published in peer-reviewed scientific journals. Two of these present empirical data from a survey study among physicians in Switzerland, and three further articles attend to conceptual challenges making a theoretical contribution to the field. Together, they engender a more nuanced understanding of the challenges mentioned above. Although the insights gained are of general relevance, they are of particular significance to the situation in Switzerland, as the broader National Research Programme (NRP-67) encompassing the present thesis aims to provide solid grounds to inform Swiss policy.

The five reviewed publications constitute the main part of the present thesis, embedded in a preceding introductory section that captures the essentials of decision-making capacity

by reviewing the existing literature. Terms are clarified and the ethical and legal grounds of decision-making capacity are set out, followed by an outline of the key challenges. After presentation of the original articles, insights are discussed with a view to integrating knowledge and drawing conclusions and recommendations for policy and clinical practice. The dissertation closes by considering promising future directions within this field of inquiry.

2 Decision-Making Capacity or Competence?

The evident complexity of this subject is increased by the use of two different terms in the literature—*decision-making capacity* and *competence*—which evoke disagreement about their distinctive features. While some hesitate to draw any distinction between the two terms (e.g., Grisso & Appelbaum, 1998a; Kim, 2010), others emphasize their disparity without entirely negating their relatedness. The differences tend to align with demarcations between the disciplines involved: while decision-making capacity is regarded as a clinical status to be determined by a healthcare professional, competence denotes a legal status as judged by a legal professional (e.g., Ganzini, Ladislav, Nelson, & Fox, 2004; Marson, 2001; O'Connor, 2010). Differentiation between the two terms further emphasizes the specific inherent characteristics of each concept. While competence is conceived as a categorical judgment, decision-making capacity is sometimes marked and treated as a dimensional concept or as a matter of degree in relation to functional abilities (Kitamura & Takahashi, 2007; Sturman, 2005). For example, Royall (2002, p. 1885) suggested that „'Capacity' can be thought of as a functional ability intrinsic to the individual, whereas 'competency' is a social status conveyed upon them".

Both of these perspectives have been contested in favor of the interchangeable usage of decision-making capacity and competence, both designating a dichotomous judgment. Grisso and Appelbaum (1998a) argued that the distinction between legal and medical notions, though technically correct, breaks down in practice. Courts and statutes often use the term decision-making capacity—or just *capacity*—to refer to an adjudicated determination of competence (Kim, 2010). Because the court is rarely involved in normal everyday clinical practice, clinical determination commonly represents *de facto* adjudication, and physicians' judgment alone determines whether or not the patient retains decisional authority. Where the courts are involved, the expert opinion of physicians (mostly psychiatrists) is sought (Kim, 2010). On the other hand, a dichotomous

understanding is advocated with regard to the function of competence determination within the doctrine of informed consent, clearly assigning decisional authority either to the patient or to surrogate decision-makers (Buchanan & Brock, 1989). „Persons are judged, both in the law and more informally in health care settings, to be either competent or incompetent to make a particular decision—even though the underlying capacities and skills forming the basis of the judgment are possessed in different degrees“ (Buchanan & Brock, 1989, p. 27). Exactly these underlying capacities and skills are referred to when decision-making capacity is conceived as a gradual concept, rendering it purely descriptive of the inherent characteristics of a person and omitting the judgmental or normative component—or, as Royall (2002) puts it, the social status conveyed upon them.

It follows that the view of decision-making capacity as coequal with competence differs from the understanding of decision-making capacity as those mental abilities of relevance to competence judgments. Clarification of this usage is therefore required for any sensible examination of the subject. In the present thesis, decision-making capacity and competence are used interchangeably, referring to a professional judgment that may be legal or clinical. Accordingly, in discussing mental abilities that are relevant for competence or for decision-making capacity, other terms will be used, such as *capacities* (plural), *mental abilities*, or *faculties*. The use of adjectives like *capable* and *incapable* or *competent* and *incompetent* will also imply a judgment. In Switzerland, the only existing expression is *Urteilsfähigkeit*, *capacité de discernement*, or *capacità di discernimento*, respectively, used here as equivalent to *decision-making capacity* or *competence*.

3 Ethical and Legal Foundations

The concept of decision-making capacity is inextricably bound to the legal doctrine of informed consent and to its underpinning moral principle of respect for autonomy, the moral principle of beneficence, and any derived rights, duties, and obligations (Beauchamp & Childress, 2009; Faden & Beauchamp, 1986). An appreciation of how competence judgments are embedded in the prevailing legal and moral frame is fundamental to a full understanding of their meaning and function.

3.1 Moral Principle of Beneficence

The principle of beneficence is deeply entrenched in common morality and refers to the moral obligation to act for the benefit of others in helping them to promote their interests,

often by preventing or removing harms. Related to the virtue of benevolence, it connotes acts of mercy, kindness, and charity, and is suggestive of altruism, love, and humanity (Beauchamp & Childress, 2009). The concept of beneficence is rooted in ethical theories dating back to Hume, Kant, and Mill, and found expression in the earliest medical codes of ethics, such as the ancient *Hippocratic Oath* (Edelstein, 1943) and its modern version, the *Declaration of Geneva* (World Medical Association, 1948), which asserts that the health of patients will be the physician's first consideration. Beneficence, then, constitutes a specific obligation within the patient-physician relationship, reflecting the nature and ends of medicine as healing, which is a fundamentally beneficient undertaking. It includes the obligation to alleviate disease and injury if there is a reasonable hope of cure and to eliminate or minimize pain, suffering, and disability (Faden & Beauchamp, 1986).

3.2 Moral Principle of Autonomy

The value of autonomy and the corresponding obligation to respect the autonomy of others is a guiding principle in modern Western societies in particular, where individualism is highly esteemed. As a central value in both the Kantian tradition and Mill's utilitarian liberalism (Spriggs, 2005), autonomy is a core concept in moral philosophy. Personal autonomy relates to the individual's self-governance or self-determination and is held to have intrinsic as well as instrumental value in promoting well-being (Buchanan & Brock, 1989). Both the moral principle of respect for autonomy and the legal notion of a right to self-determination flow from this value of self-rule and entail the negative obligation of non-interference with persons possessing and exercising the capacity for self-governance and the positive obligation to enable and promote autonomous conduct (Beauchamp & Childress, 2009).

As compared to the principle of beneficence, respect for autonomy has found its way into medical ethics relatively late in the mid-twentieth century, together with the emerging legal doctrine of *informed consent*, embodying the patient's right to self-determination. First elaborated in the *Nuremberg Code* (Trials of war criminals before the Nuremberg military tribunals under control council law No. 10, 1949), and later in *The Belmont Report* (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978), the principle of respect for persons and their autonomy first entered research ethics before being adopted soon after in the field of clinical practice (Faden & Beauchamp, 1986; Spriggs, 2005). It obliges healthcare professionals to respect a patient's treatment decision and „to disclose information, to probe for and ensure understanding

and voluntariness, and to foster adequate decision making“ (Beauchamp & Childress, 2009, p. 104).

3.3 Doctrine of Informed Consent

Informed consent is as much a legal doctrine as a moral right of patients that generates moral obligations for physicians. It is interpreted in the legal tradition as grounded in, and justified by, the moral principle of respect for autonomy (Faden & Beauchamp, 1986). In essence, it requires healthcare professionals to obtain consent from their patients to authorize a particular medical intervention. Informed consent is normally defined by the prerequisites necessary for *valid* authorization of medical treatment, in which (1) there is thorough *disclosure* to the patient of relevant information; (2) the patient *comprehends* the disclosure; (3) the patient decides *voluntarily;* and (4) the patient is *competent* to make the decision (Faden & Beauchamp, 1986).

According to Faden and Beauchamp (1986), these four conditions properly reflect the rules governing informed consent in institutional contexts and public policy embracing one particular understanding of informed consent as *effective consent* or *effective authorization.* Such consent is legally or institutionally valid in that it complies with the rules and with institutionally settled requirements and standard practices. However, it is important to recognize that this sense of informed consent is not necessarily congruent with an understanding of informed consent as *autonomous authorization,* which is grounded in a theory of autonomy or autonomous action (Faden & Beauchamp, 1986). For example, the abovementioned *disclosure* condition does not constitute a necessary prerequisite for autonomous authorization, as persons can be otherwise knowledgeable and able to provide well informed consent without having received information from their physician.

It makes sense to define informed consent as an autonomous authorization deriving from a theory of autonomy, which accords with its purpose in medicine to protect the value of autonomy and to safeguard patients' right to self-determination. In other words, respect for autonomy can come into effect only where autonomy is exercised. In this sense, informed consent is understood as the patient's practice of their autonomy, resulting in authorization (consent) or non-authorization (refusal) of treatment (Faden & Beauchamp, 1986). It follows that the conditions for valid informed consent (including the *competence* condition) are best derived from the defining elements of autonomy with regard to persons and action.

Faden and Beauchamp (1986) further claim that policy-oriented definitions of informed consent (that is, *effective* consent) should maximally conform with a theory-driven definition of *autonomous* consent, which serves as a benchmark providing normative orientation. Issues of feasibility and implementation in concrete healthcare contexts may limit this requirement. The present thesis is predominantly concerned with decision-making capacity as a condition for *autonomous* consent, although account is also taken of practical constraints.

3.4 Gatekeeping Function of Decision-Making Capacity

Decision-making capacity is regarded as an essential element in both *effective* and *autonomous* consent. In line with a theory-driven understanding of informed consent, it is usually equated with a patient's capacity for self-determination or autonomy (e.g., Beauchamp & Childress, 2009; Freyenhagen, 2009; Mackenzie & Rogers, 2013; Owen, Freyenhagen, Richardson, & Hotopf, 2009; Radoilska, 2012b).

Moreover, according to Faden and Beauchamp (1986), decision-making capacity functions as a *gatekeeper* for informed consent.[1] Judgments about a person's competence determine from whom consent should be solicited; if a person is competent (possessing the capacity for self-determination), informed consent should be sought from that person—an obligation derived from the moral principle of respect for patients' self-determination. By contrast, if a person is incompetent (lacking the capacity for self-determination), other mechanisms must be instituted for the authorization of medical treatment—an obligation deriving from the moral principle of beneficence (Faden & Beauchamp, 1986).[2] In this way, competence judgments determine whether or not a patient retains decisional authority—that is, whether or not he is granted a right to self-determination.

3.5 Balancing Moral Principles

Moral principles often conflict, as do the principles of autonomy and beneficence, which are obviously important to the concept of competence. Patients can exercise their autonomy while choosing an alternative that is detrimental for their health—for example, they may forgo life-saving treatment. In such instances, healthcare practitioners are torn between the

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[1] See also Beauchamp and Childress (2009).

[2] Measures of surrogate decision-making such as advance directives or durable powers of attorney must be based on a patient's presumed will. Objective best interest considerations become relevant only if there are no information about the presumed will of the patient (Beauchamp & Childress, 2009).

prima facie moral obligation to respect a patient's choices and the competing obligation to alleviate disease and promote the patient's welfare.[3]

Normally, the determination of actual obligation is a complex endeavor. In their influential work *Principles of Biomedical Ethics,* Beauchamp and Childress (2009) emphasized that none of the four principles they propose—*autonomy, beneficence, non-maleficence,* and *justice*—generally takes moral priority over the others. Rather, there is a process of weighing and balancing in deciding which of two or more conflicting principles should prevail in a particular situation. How, then, is one to balance patient autonomy and patient well-being, for instance, when the patient forgoes live-saving treatment? The doctrine of informed consent provides clear guidance in this regard, where even the balancing of moral principles seems to be overruled by clear-cut rules regarding the establishment of priorities: if the patient is competent, decisional authority lies completely with him, and his decision to forgo treatment is to be respected. Thus, absolute precedence to self-determination is given over the principle of beneficence on condition that the patient is competent.[4] Against this, if the patient is incompetent, beneficence often takes precedence (Buchanan & Brock, 1989).[5]

In this respect, decision-making capacity not only dictates whether or not a patient is given a right to self-determination but also whether self-determination is to be given priority over other principles. Competence judgments therefore determine, replace, or better perhaps incorporate the balancing of moral principles, as further analyses will show. On any account, it is this intricate relation to moral principles that renders decision-making capacity so crucial from an ethical and legal perspective.

3.6 Medical Paternalism

In the medical ethics literature, the notion of medical paternalism is used to circumscribe the conflicting and potentially problematic relation between beneficence and autonomy. Beauchamp and Childress (2009) define paternalism as

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[3] Autonomy is said to have also instrumental value for a person's well-being. Therefore, it is argued that the best interest is intimately linked with the preferences of the autonomous person (Pellegrino & Thomasma, 1988). In this case, beneficence and respect of autonomy coincide and no conflicts arise. As against this, it is argued that beneficence is distinct and directly conflicts with respect of autonomy on the basis that there are potentially diverging standards of best interest (objective versus subjective standards) (Beauchamp & Childress, 2009).

[4] The only limitations on the competent patient's right to self-determination applies when treatment refusal imposes significant health risks for others (e.g. serious epidemic disease) (Buchanan & Brock, 1989).

[5] This is particularly true in those cases where the presumed will of the patient is unknown and objective best interest considerations come to the fore.

> *the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden*. (p. 208)

Throughout the history of medical ethics, healthcare practitioners have engaged in paternalistic interventions, invoking the principle of beneficence by deceiving, lying, manipulating, or failing to disclose information, as well as by coercing patients on the basis of an intention to do good (Beauchamp & Childress, 2009; Faden & Beauchamp, 1986). Yet, the moral status of paternalistic interventions is contested (e.g., Dworkin, 2014). In this regard, it is essential to distinguish between *soft* and *hard paternalism;* while *soft paternalism* applies to instances where a patient's nonautonomous preferences are overriden, *hard paternalism* restricts autonomous conduct (Beauchamp & Childress, 2009). There is general agreement that soft paternalism is morally unproblematic because there is no real conflict between the principles of autonomy and beneficence (Beauchamp & Childress, 2009). Again, respect for autonomy holds only in instances where autonomy is excercised, and controversies therefore essentially concern hard paternalism.[6]

Without delving deeper into these debates, there is an obvious parallel between medical paternalism and its moral justification and the doctrine of informed consent, in which decision-making capacity is the decisive pivot. Medical paternalism or prioritization of the principle of beneficence over autonomy is morally and legally justified (only) in the case of incompetence. Yet, in taking this gatekeeping position, competence judgments become particularly susceptible to abuse, in that a physician's intention to enforce his own conception of the good on a patient is simply achieved (without risking accusations of unjustified or hard paternalism) by an incompetence judgment. In such cases, one may speak of disguised unjustified paternalism. Such misuse can be deliberate, however, less conscious influences on competence judgments are perhaps even more frequently making unjustified medical paternalism a recurring issue in the various discussions of competence.

3.7 Legal Basis in Switzerland

Despite the general significance of decision-making capacity, the concept as a legal term is variously explicated across jurisdictions. For present purposes, the legal basis in Switzerland is outlined here.

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[6] Some authors claim that the definition of paternalism necessarily involves a restriction of autonomous conduct. In this respect, restricting nonautonomous choices is not paternalistic and the term *soft paternalism* therefore misguiding (Beauchamp & McCullough, 1984).

The informed consent of a patient is relevant in Swiss law because each medical intervention constitutes a violation of a patient's physical (and possibly mental) integrity. Neutralization of the illegality of such violation is achieved only by consent of the patient or, if he is incompetent, by consent of his legal representative (Büchler & Gächter, 2011). The patient's physical and mental integrity is protected by the right to life and personal liberty as enshrined in the constitution (Article 10, BV), by personality rights in civil law (Article 28, ZGB), and by the offence of bodily injury in criminal law (Article 111ff., StGB).

On that basis, physicians are legally obliged to obtain consent for each medical intervention of the legally appointed authority. It follows that a medical intervention is unlawful (a) if a competent patient does not give consent or refuses treatment and (b) if it is grounded on the (legally invalid) consent of an incompetent patient (Aebi-Müller, 2014). Also in Swiss law, then, decision-making capacity is treated as the gatekeeper for a patient's right to self-determination (Aebi-Müller, 2014).

Decision-making capacity is defined as follows in Article 16 of the Swiss Civil Code:

> *A person is capable of judgement within the meaning of the law if he or she does not lack the capacity to act rationally by virtue of being under age or because of a mental disability, mental disorder, intoxication or similar circumstances.*[7]

The definition contains a double negation, emphasizing that competence is the normal condition, which is reflected in the legal presumption of competence (Aebi-Müller, 2014).[8] Furthermore, the term decision-making capacity incorporates two necessary elements: (a) a *subjective component* concerning the *capacity to act rationally* and (b) *objective causes* (age, mental disability, mental disorder, intoxication or similar circumstances).

With regard to the subjective component, the legal doctrine further distinguishes between the *ability to form one's own and reasonable will* (*Willensbildungsfähigkeit*) and the *ability to act according to one's will* (*Willensumsetzungsfähigkeit*) (Aebi-Müller, 2014). Both abilities are in need of further specification.[9] Importantly, impairment of these abilities is not sufficient to support a legal judgment of incompetence, as they must be caused, at least partially, by an objectively verifiable somatic or mental condition. According to Aebi-Müller (2014), these are broadly defined and include severe physical disease, high fever, coma, medical sedation, state of shock or severe agitation in addition to the abovementioned causes.

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[7] German text: „Urteilsfähig im Sinne dieses Gesetzes ist jede Person, der nicht wegen ihres Kindesalters, infolge geistiger Behinderung, psychischer Störung, Rausch oder ähnlicher Zustände die Fähigkeit mangelt, vernunftgemäss zu handeln."

[8] See section 4.1.

[9] See section 5.1.

However, the mere presence of these conditions does not justify an judgment of incompetence; the decisive question is whether or not these conditions impact on a person's ability to will something and then to act accordingly.

Swiss legal provisions further specify aspects of decision-making capacity that are of general concern, shared with other jurisdictions, or discussed as well within related disciplines such as medical ethics. The following sections address both consensus and controversies in relation to these broader concerns.

4 Matters of Consensus

Although decision-making capacity is a controversial and much-discussed concept, there are some important agreed principles that generally guide competence evaluations (Berghmans, Dickenson, & Rudd, 2004).

4.1 Legal Presumption

The legal presumption of competence in the Swiss jurisdiction has already been mentioned.[10] It entails a moral imperative and is relevant in terms of liability. From a moral perspective, the view is taken that an adult patient ought to be considered competent unless there are sufficient grounds for the opposite view and only if there are substantial doubts should a patient's competence be challenged (Trachsel, Hermann, & Biller-Andorno, 2014a). Clearly, there are cases of incompetence that are obvious at first sight, in which the presumption of competence holds but is simply refuted (e.g., comatose patients, cases of severe intoxication). In all other cases, including patients suffering from a mental disorder, somatic illness or disability, competence is generally assumed and a more detailed evaluation of competence is indicated if it is doubted (Berghmans et al., 2004). This serves primarily to prevent any unreflective or unjustified association of incompetence with particular conditions. As Grisso and Appelbaum (1998a) have highlighted, incompetence is related but not identical to an impaired mental state. This claim aligns with the twofold requirement set out in the Swiss law of an objective cause and an additional impairment of functional abilities. In support of this claim, empirical studies have repeatedly demonstrated that persons with mental and cognitive disorders often retain the relevant mental abilities for competence (Okai et al., 2007). Taking the legal presumption seriously prevents hasty or short-cut conclusions about a patient's decision-making capacity in favor

[10] See section 3.7.

of an adequate and thorough competence evaluation, reflecting an *a priori* respect for a person's autonomy (Carpenter, 1999).

The legal presumption is also important from a liability perspective. Normally, if a patient is considered competent because there are no reasons to doubt their competence and this judgment is called into question, reference can be made to the legal presumption, and the appellant must prove incompetence (Aebi-Müller, 2014). However, Swiss law also speaks of an invalidation of the presumption of competence and a reversed onus of proof in instances where the patient suffers from obvious and constant impairments of mental abilities or is very young (Aebi-Müller, 2014).[11] In such cases, it may be difficult to defend a competence judgment solely by reference to the legal presumption of decision-making capacity. Thus, it appears that the moral reasons for presuming competence—preventing unjustified short-cut judgments—conflict in certain instances with liability concerns and the burden of proof. While it is morally appropriate to assume that a mentally disabled person is able to decide autonomously, this presumption can become rather insignificant in defending a competence judgment in the case of an appeal.

4.2 Specificity of Judgment

Patients are not deemed generally incompetent but always with regard to a particular legal act or treatment decision, and at a particular point in time. Decision-making capacity is therefore both time- and decision-specific (Buchanan & Brock, 1989; Grisso & Appelbaum, 1998a; President's Commission for the Study of Ethical Problems in Medicine, 1982).[12]

The reason for evaluating competence in respect of a specific decision is that various treatment decisions make differing demands on a patient's abilities by virtue of their varying complexity (Grisso & Appelbaum, 1998a). For example, adequate understanding of a complex procedure requires better mental abilities than adequate understanding of a simple procedure. Therefore, a patient can be deemed competent to make an ordinary decision (for example, about an antibiotic treatment) but incompetent to decide on a more complicated treatment such as a surgical intervention.

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[11] See also judgment of the federal court 5C.259/2002 of 6 February 2003 E. 1.3.

[12] In Swiss law, support for this maxim is provided by the federal court: „Zu beachten ist ferner, dass das schweizerische Recht keine abstrakte Feststellung der Urteilsfähigkeit kennt. Das Gericht hat vielmehr stets zu prüfen, ob die fragliche Person im konkreten Fall, das heisst im Zusammenhang mit einer bestimmten Handlung oder bei der Würdigung bestimmter tatsächlicher Gegebenheiten, als urteilsfähig angesehen werden kann." (BGE 124 III 5E.1b).

On the other hand, time-specificity is justified on the basis that the functioning of relevant mental abilities can fluctuate, and intermittent states of confusion or weakness can alternate with lucid moments. In cases of dementia with Lewy Bodies, for example, such cognitive fluctuations are a core characteristic (Trachsel, Hermann, & Biller-Andorno, 2014b). Fluctuating mental states and abilities pose a great challenge in evaluating decision-making capacity, not least because practical constraints in the hectic setting of clinical practice may not always allow for repeated or postponed evaluations.

4.3 Process rather than Outcome

The moral principle of autonomy entails an obligation to respect a person's self-determined choices, even where these are unwise or irrational. For that reason, the *outcome* of a decision *per se* is never a criterion on which to deem a patient incompetent (Berghmans et al., 2004; Buchanan & Brock, 1989). Instead, there is agreement that incompetence judgments must always refer to impairments of the underlying *decision-making process* (Buchanan & Brock, 1989; Grisso & Appelbaum, 1998a).[13] To deem a patient incompetent just because he decides to act against a physician's advice would be illegitimate, clearly reflecting unjustified medical paternalism. However, the scope of the decision-making process is controversial. There is ongoing debate as to whether the criteria for decision-making capacity should pertain only to the process in a narrow sense or more braodly to the motives (e.g., beliefs, values, emotions) underpinning a choice and informing the decision-making process (e.g., Banner, 2013). It is further contested whether consideration of the decisional outcome, and especially of the risks entailed in a decision, should be totally excluded from competence judgments. While it is unambiguously clear that the outcome *per se* is not indicative of incompetence, it has been argued that the juxtaposition of the consequences of a decision with patient characteristics is essential for meaningful competence judgments (Brock, 1991; Grisso & Appelbaum, 1998a; Kim, 2010). These contested issues are further elaborated in section 5.

4.4 Support and Promotion

The moral obligations deriving from the principle of autonomy involve both negative obligations of non-interference and the physician's efforts to foster and enable self-

[13] In this respect, the expression used in the Swiss Civil Code capacity to act rationally is indeed highly ambiguous, not clearly indicating whether acting rationally refers to the outcome or the process. Yet, the specifications in the legal doctrine provide more clarity in this regard.

determination in their patients (Beauchamp & Childress, 2009). There is unconditional agreement that patients' decision-making should be supported and promoted for full unfolding of their potential, perhaps eventually averting a judgment of incompetence.

Under the doctrine of informed consent, the *disclosure* requirement is a legally enforced provision for meeting these moral obligations (Büchler & Gächter, 2011). Clearly, the manner of disclosing information must further accommodate patients' needs and level of education (Grisso & Appelbaum, 1998a). Empirical research suggests that appropriate adaptation of disclosure does indeed impact positively on decision-making capacity or on relevant mental abilities (Carpenter, 2000; Jacob et al., 2005; Palmer, Nayak, Dunn, Appelbaum, & Jeste, 2002; Wong, Clare, & Holland, 2000).

Optimization of patients' decision-making can additionally be achieved by a range of other strategies, including deferral of the competence evaluation to a later time, changing medication, encouraging patients to exchange with persons close to them, allowing the patient to be accompanied by someone close, creating a relaxed and comfortable atmosphere, allowing time for patients to feel at ease in telling their stories, or by acknowledging and discussing psychodynamic issues (Grisso & Appelbaum, 1998a).

4.5 Beyond the Descriptive

It is widely acknowledged in both the legal and ethics literatures that decision-making capacity involves more than the mere description of patient characteristics (Berghmans et al., 2004; Charland, 2001).[14] Normative considerations play an essential and unchallenged part in competence determinations, yet despite general recognition of the normativity of competence, its exact scope and meaning remains fuzzy, and different, more or less explicit understandings seem to circulate. An examination of the controversies and challenges introduced in the following sections is relevant to a fuller understanding of this intricate matter.

5 Controversies and Challenges

The literature on decision-making capacity can be divided into conceptual and empirical investigations. In terms of conceptual analyses, three relatively distinct subject areas can be identified, each posing particular challenges: (a) the definition of relevant criteria in terms of patient characteristics; (b) the role and significance of the consequences of a decision

[14] The distinction between the normative and the descriptive has already been introduced in section 2.

(known as risk-relativity); and (c) the evaluation process and standardization of assessment.

5.1 Criteria

As a concept, decision-making capacity resides at the intersection of philosophy, medicine, psychology, and law. This multidisciplinarity is most clearly to be seen in the efforts to define relevant mental abilities or, more generally, relevant patient characteristics. In section 3, a relationship was established between competence and a patient's capacity for self-determination, conjoining competence with the philosophical concept of *personal autonomy,* which is extensively and hotly debated. While philosophy gives meaning to self-determination, psychology offers profound knowledge on the nature and boundaries of actual human decision-making. This is complemented by psychiatry's important insights into pathological deviations. And finally, jurisdictions and legal doctrines also inform the definition of standards for decision-making capacity. An ideal definition of criteria would take all these perspectives into account, balancing the various requirements they entail. In the following, a brief summary of personal autonomy is followed by an outline of the prevailing account in the medical ethics literature, establishing four criteria on the basis of U.S. case law. Existing criticisms of these standards are presented, followed by a brief appraisal of the equivalent specifications in Swiss legal doctrine.

5.1.1 Capacity for Self-Determination

The concept of personal autonomy is complex, multifaceted, and much disputed, and the literature on the topic is vast. Within the scope of this thesis, it not possible to scrutinize these various perspectives in detail or to explain how they differ. The modest aim of this brief outline is to focus on the core idea of personal autonomy and the commonalities between different accounts.

In comparison to metaphysical accounts of autonomy such as Kant's, accounts of *personal autonomy* are concerned with the descriptive properties or conditions for self-governance or self-determination—either with regard to specific actions and choices or to the person in a more global sense (Oshana, 2006).

Self-determination is affected by both internal and external conditions (Mackenzie & Rogers, 2013; Oshana, 2006). External threats that can inhibit the exercise of autonomy include manipulation, coercion, repression, and extortion, among others (Mackenzie & Rogers, 2013); the *voluntariness* condition in the doctrine of informed consent proposes to

capture such influences.[15] Internal conditions relate to the psychological features, states, or abilities that enable autonomous choices. These internal properties, which can be threatened in various ways, bear directly on the concept of decision-making capacity.

In very broad terms, according to Marilyn Friedman (2003), the autonomous person

> *[…] chooses or acts in accord with wants and desires that she has self-reflectively endorsed, and her endorsement is somehow a part cause of her behavior* (p. 5).

Or as Marina Oshana (2006) puts it:

> *A person is autonomous to the extent that she rules herself; self-rule allegedly occurs when the person executes the skills needed to direct her behavior in light of values, principles, beliefs and desires that she has authenticated and so made her own*. (p. 21)

As these definitions suggest, the internal conditions for self-determination involve both *skills*—minimal reflective capacities of sorts—and *authenticity.* With regard to the latter, in order to count as autonomous, a person's decision and her underlying values, beliefs, and desires must be her "own" in some relevant sense, in that they must cohere with her sense of who she is and what matters to her (Mackenzie & Rogers, 2013). While different accounts of personal autonomy tend to agree on these basic elements, disagreement crystallizes with regard to what is involved in the process of reflection, how reflection secures autonomy, and the meaning of the notion of *one's own* (Mackenzie & Stoljar, 2000).

5.1.2 Traditional U.S.-Criteria

Research on medical decision-making capacity began to flourish in the late 1980s. In the U.S., the *MacArthur Civil Competence Project* was launched to investigate informed consent and patients' decision making capacities in a research program that lasted from 1989 to 1997. In this context, on the basis of American case law, Paul S. Appelbaum and Thomas Grisso identified and specified four standards or mental abilities that are considered relevant for competence.[16] They developed a standardized instrument—the *MacArthur Competence Assessment Tool For Treatment (MacCAT-T)*—to assess those abilities (Grisso & Appelbaum, 1998b), validating it in a series of innovative empirical studies (Appelbaum & Grisso, 1995; Grisso & Appelbaum, 1995; Grisso, Appelbaum, Mulvey, & Fletcher, 1995). Appelbaum and Grisso's four-standard model has become canonical as the prevailing account of competence, exerting an ongoing influence in the field of medical ethics. The

[15] See section 3.3.

[16] Important preliminary work has been done by Roth, Meisel, and Lidz (1977), Appelbaum and Roth (1982), and Appelbaum and Grisso (1988).

model encompasses the following criteria: (1) *understanding*, (2) *appreciation*, (3) *reasoning*, and (4) *expressing a choice* (Grisso & Appelbaum, 1998a).[17]

Understanding describes the ability of the patient to understand the information that has been disclosed to them in the course of the informed consent procedure, including information about the disorder, treatment alternatives, associated risks and benefits, and the course of the disorder if it remains untreated.

Appreciation refers to the ability to acknowledge that one is suffering from a particular disorder (i.e., insight into the disorder) and to the ability to appreciate the consequences for one's own circumstances of both the disorder and the potential treatment options. This includes acknowledgment of the possibility that treatment may be beneficial (i.e., insight into the necessity of treatment). Specifically, it purports to capture patients who fail to accept the relevance of their situation due to so-called *patently false beliefs*, often resulting from delusions or strong denial (Saks, 1991). In order to deprive the patient of *appreciation*, such beliefs must be substantially irrational, reflecting a considerable distortion of reality. These must be distinguished from objectively reasonable beliefs that may equally lead to a rejection of the disorder or of the effectiveness of treatment. For instance, a patient may doubt the benefit of a specific treatment because of negative previous experiences of similar interventions, but this would not undermine *appreciation* in the same way as patently false beliefs. As Grisso and Appelbaum (1998a) noted, mere disagreement with the physician's characterization of the situation is never an adequate reason for questioning a patient's competence.

Reasoning describes the patient's ability to engage in a logical process of weighing treatment options. This encompasses the ability to stay focused on the decision-making task, to envision the whole range of treatment options, to consider risks and benefits (including practical consequences for one's everyday life), to assess their likelihood and evaluate their desirability on the basis of one's own values, and to deliberate on or "work with" the information to reach a decision that follows logically from the patient's reasoning.

Finally, *expressing a choice* refers to the ability to communicate a decision. This ability may be impaired either because of a total inability to communicate (e.g., in comatose patients) or because of ambivalence that prevents arrival at any choice or causes persistent vacillation between options.

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[17] Throughout this thesis, the four standards are written in italics whenever they refer to the definitions of Grisso and Appelbaum (1998a).

Clearly, Appelbaum and Grisso worked hard to provide a comprehensive and differentiated account of decision-making capacity, and the definition and specification of these four capacities undoubtedly led to substantial improvements in the understanding and evaluation of competence. Nevertheless, subsequent analyses have demonstrated that the traditional approach is insufficient and remains in need of further refinement.

5.1.3 Criticism: Cognitive Bias

The most prominent criticism of the traditional model concerns its predominantly cognitive orientation. Specifically, it is argued that the four criteria overemphasize intellectual capacities and fail to take sufficient account of emotional factors. As Charland (1998b) notes, *understanding* and *appreciation*—as operationalized in the MacCAT-T—are concerned with the intellectual grasp of factual information, either generally (*understanding*) or with regard to one's own situation (*appreciation*) while emotional components of these mental operations are ignored. Similarly, operationalization of the *reasoning* standard in line with rational choice theories implies that decisions are reached on the basis of purely analytical and conscious deliberation; again, there appears to be no room for affective imports or intuitive reasoning (Breden & Vollmann, 2004). The MacCAT-T is further accused of neglecting the importance of personal values, associated biographical experiences, and their affective connotations in patients' decision-making (Breden & Vollmann, 2004; Karel, Gurrera, Hicken, & Moye, 2010). The failure to consider the authenticity of a patient's choice or their underlying values excludes a further important aspect of personal autonomy.

Interestingly, on reading Grisso and Appelbaum (1998a), there is no sense that they are totally ignorant of the emotional, intuitive, or valuational aspects of decision-making. On the contrary, in describing and specifying each criterion, they draw a rather nuanced picture that puts their brief definition of each standard into perspective. They illustrate, for instance, how *appreciation* is dismissed because of a patient's depressive hopelessness, which prevents her from realistically appraising her situation. Clearly, then, Grisso and Appelbaum appreciate at least the negative impacts of affective states on competence.

With regard to *reasoning,* they also acknowledge that people have different decision-making styles, where some prefer to choose impulsively or to rely on their emotions or intuitions. Moreover, they clearly state that these persons have the right to do so, as long as no mental or cognitive disorder is preventing them from doing otherwise. In explicating the *reasoning* standard, they also refer to patients' personal values and their role in

evaluating consequences, and there are many more examples of this sort. In summary, it seems that criticism of the traditional model relates less to the diametrically opposed views of Grisso and Appelbaum and their opponents than to the the insufficient, reductionist, and biased operationalization of criteria in the MacCAT-T. In short, the problem lies more in the translation of concepts into standardized measures than in the concepts *per se*.

5.1.4 Criticism: Procedural Bias

With the enactment of the *Mental Capacity Act 2005* (Department for Constitutional Affairs, 2007), stipulating legally binding criteria in England and Wales, another sort of criticism has emerged that to some extent impacts on the traditional model of Grisso and Appelbaum. The Mental Capacity Act 2005 sets down the following standards: (1) the ability to understand information relevant to the decision; (2) the ability to retain that information; (3) the ability to use or weigh that information as part of the decision-making process; and (4) the ability to communicate a decision. In sum, these capacities strongly echo the traditional criteria other than the *appreciation* standard, for which there is no equivalent in the Mental Capacity Act 2005, inviting criticism of the Act as overly focused on procedural aspects (Banner, 2012; 2013; Freyenhagen & O'Shea, 2013).

On close examination, the *appreciation* standard is found to be concerned not with *formal* requirements pertaining to the processing of information *(*as in procedural standards such as *understanding, reasoning,* and *evidencing a choice)* but with the *content* of *beliefs* serving as inputs to the decision-making process (Grisso & Appelbaum, 1998a). In other words, *appreciation* is concerned with *substantive* aspects and judgments of the irrationality or reasonableness of beliefs underlying or informing choice. According to the critics of the Mental Capacity Act 2005, substantive considerations are necessarily involved—implicitly or explicitly—in any meaningful determination of competence. This is especially true in the context of mental disorders where strong moral intuitions concerning a patient's incompetence often cannot satisfactorily be captured by a purely procedural standard (Freyenhagen & O'Shea, 2013; Holroyd, 2012). Here, in addition to the content of *epistemic beliefs* (distortion of reality), anything that motivates a decision—including *values* and *emotions*—is relevant (Banner, 2012). In this respect, the traditional model falls short, as it fails to take proper account of the adequacy of the affective reasons and values underpinning a decision.

On the other hand, the inclusion of substantive elements in evaluations of decision-making capacity is not uncontroversial, with ongoing debate as to whether or not competence (and,

more generally, the concept of personal autonomy) is *content-neutral (value-neutral)* or *content-laden (value-laden)* (Freyenhagen, 2009; Freyenhagen & O'Shea, 2013; Owen et al., 2009). To say that a patient's values, beliefs, and emotions are inappropriate necessarily involves a normative judgment. Moreover, substantive requirements set limits to pluralism, which is highly cherished in modern, liberal-democratic societies. Content-laden judgments carry the risk of being overly arbitrary or facilitating unwarranted and disguised paternalism (Radoilska, 2012a).

The prevention of such negative effects is exactly the motivation for a purely procedural standard of competence. However, as mentioned above such a standard is often insufficient; delusions, for example, would not identify a patient as incompetent under a pure procedural standard. Moreover, it is argued that evaluative elements are also necessarily involved in the context of an ostensible procedural account. For example, Holroyd (2012) suggested that judgments about a person's ability to weigh information must be relative to the values this person endorses. By saying that a patient is able to reason and weigh information, it is implied not only that the reasoning is logically consistent but also that it is informed by specific evaluative commitments and rankings. For instance, refusal of life-saving treatment in favor of attendance at a one-off sale of designer bags would appear to be an evaluative mistake, calling into question the individual's ability to weigh information. Thus, judging *reasoning*—an apparent procedural standard—also involves the assignment of appropriate weights to single items of information and is therefore not value-free (Banner & Szmukler, 2013). Certainly, a range of values is acceptable, but certain beliefs, commitments, and rankings will inevitably be ruled out (Holroyd, 2012).

In conclusion, it is a mistake to maintain that the conditions for decision-making capacity are value-neutral (Owen et al., 2009). Any attempt to adhere rigidly to a purely procedural understanding of competence runs the risk that value judgments on the part of the evaluator will remain unreflected, flowing implicitly into competence determinations and potentially resulting in disguised and unwarranted paternalism (Freyenhagen & O'Shea, 2013). A more straightforward approach would be to explicitly acknowledge substantivism and confrontation, as well as searching for solutions to the problems of arbitrariness and the risk of unwarranted paternalism (Banner, 2013; Freedman, 1981; Freyenhagen & O'Shea, 2013). Beside epistemic beliefs, emotions and values underpinning a choice also deserve substantive scrutiny.

5.1.5 Specifications in Swiss Legal Doctrine

As already outlined, the Swiss legal doctrine defines two broad categories of mental abilities that are relevant for competence: (1) the *ability to form one's own and reasonable will* (*Willensbildungsfähigkeit*) and (2) the *ability to act according to one's will* (*Willensumsetzungsfähigkeit*).[18] These abilities are further specified and assigned to subcategories. In the following, the accounts of Volker Dittmann (2008) and Regina Aebi-Müller (2014) are contrasted with the traditional U.S. model (see Table 1).[19]

For Aebi-Müller, *Willensbildungsfähigkeit* consists of *verstandesmässige Einsicht (Intellekt); Realitätsbezug des Urteilsvermögens; Fähigkeit zur Bildung und Abwägung nachvollziehbarer Motive;* and *Fähigkeit zur Motivkontrolle und Willensbildung.* With regard to *Willensumsetzungsfähigkeit,* she provides no further specification. By contrast, Dittmann distinguishes between two *cognitive* elements (*Erkenntnisfähigkeit* and *Wertungsfähigkeit*) and two *volitional* elements (*Fähigkeit zur Willensbildung* and *Willenskraft*). The definitions are summarized in Table 1. As the definitions suggest, the accounts of Dittmann and Aebi-Müller are fairly congruent despite their differing classifications. Aebi-Müller provides an even more nuanced understanding, especially with regard to what Dittmann *(*rather vaguely*)* calls *Fähigkeit zur rationalen Beurteilung.*

The specifications provided by Grisso and Appelbaum (1998a) enable assignment of the U.S. criteria to Swiss standards.[20] Explication of the ability to grasp reality (*verstandesgemässe Einsicht; Erkenntnisfähigkeit*) by distinguishing *understanding* and *appreciation* is worthy of special mention, as is the U.S. model's lack of an equivalent for what Swiss legal doctrine calls *Willensumsetzungsfähigkeit* or *Willenskraft.* And closer examination of Swiss law confirms the relevance of substantive aspects; Dittmann, for example, speaks of a rational judgment (*vernünftiges Urteil*) with regard to a patient's ability to value (*Wertungsfähigkeit*). Even more explicit is the following statement by Aebi-Müller (2014):

> *Die dem Willensentschluss zugrunde liegenden Motive dürfen nach allgemeiner Auffassung nicht grundlegenden, anerkannten Wertvorstellungen zuwiderlaufen, sie müssen vielmehr annehmbar oder wenigstens einfühlbar sein.* (p. 13)

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[18] See section 3.7.

[19] It is not aimed at providing a comprehensive overview of the legal doctrine in Switzerland. Rather relevant aspects shall be illustrated by two recent accounts.

[20] See section 5.1.2.

Table 1. Criteria for decision-making capacity in terms of mental abilities.

Aebi-Müller (2014)	**Dittmann (2008)**	**Grisso and Appelbaum (1998)**
Willensbildungsfähigkeit		
	Cognitive elements	
Verstandesgemässe Einsicht (Intellekt): Die Fähigkeit, die Aussenwelt in ihren Realitäten zu erfassen sowie die Fähigkeit die (künftigen) Konsequenzen des eigenen Verhaltens wenigstens in groben Zügen erkennen und beurteilen zu können.	*Erkenntisfähigkeit:* Die Fähigkeit die Außenwelt zumindest in ihren Grundzügen richtig zu erkennen und sich ein adäquates Bild von der Realität zu verschaffen.	*Understanding:* The ability to understand information relevant to treatment decision making
		Appreciation: The ability to appreciate the significance of relevant information for one's own situation, especially concerning one's illness and the probable consequences of one's treatment options
Realitätsbezug des Urteilsvermögens: Die Fähigkeit, die Tragweite eines Behandlungsentscheides lebenspraktisch einschätzen zu können.	*Wertungsfähigkeit:* Die Fähigkeit zu rationaler Beurteilung und das Vermögen, sich über die Tragweite und die Opportunität der in Frage stehenden Handlung ein vernünftiges Urteil zu bilden.	*Reasoning:* The ability to process treatment information and one's preferences in a logical manner
Fähigkeit zur Bildung und Abwägen nachvollziehbarer Motive: Die Fähigkeit, eigene Motive zu bilden, kritisch abzuwägen und mit allfälligen Motivkonflikten umzugehen.		
	Volitional elements	
Fähigkeit zur Motivkontrolle und Willensbildung: Die Fähigkeit zur Impulskontrolle sowie die Fähigkeit, einen stabilen Willen zu bilden.	*Fähigkeit zur Willensbildung:* Die Fähigkeit, aufgrund gewonnener Einsicht und eigener Motive einen nach außen wirksamen Willen zu bilden, bei verschiedenen denkbaren Möglichkeiten eine Entscheidung zu treffen.	*Expressing a choice:* The ability to communicate a decision
Willensumsetzungsfähigkeit		
The ability to resist external influences as can be normally expected	*Willenskraft:* Die Kraft, gemäß gewonnener Einsicht und eigenem Willen zu handeln, d.h. auch über die Fähigkeit zu verfügen, dem Versuch einer fremden Willensbeeinflussung in normaler Weise Widerstand zu leisten.	

Aware of the risk of unwarranted paternalism and the balancing act inherent in substantive judgments, she continues:

> *Ob die für eine Entscheidung letztlich ausschlaggebenden Motive nachvollziehbar sind, hängt grundlegend mit dem Weltbild und den Wertvorstellungen des Betroffenen zusammen. Es liegt auf der Hand, dass der Dritte, der die Urteilsfähigkeit des Patienten einschätzen muss, nicht sein eigenes Weltbild als allein gültigen Wertmassstab nehmen darf. Er muss sich in das Weltbild des Patienten und in dessen Wertesystem einfühlen, solange diese nicht geradezu krankhaft sind oder auf (u.a. krankheitsbedingten oder religiösen) Wahnvorstellungen, Halluzinationen oder dergleichen beruhen.* (p. 13)

By comparison with the U.S. criteria, the Swiss doctrine generally appears to place more emphasis on patients' *own motives*, in that the expressed will of the patient must be their *own* (Honsell, Vogt, & Geiser, 2010). This is also reflected in the requirement that the patient should be able to block external influences, or at least to take ownership of the opinions of others through reflective endorsment (Aebi-Müller, 2014). Clearly, then, the concept of authenticity is more fully implied in Swiss doctrine than in the U.S. model.

Emotional factors also find consideration in the Swiss framework (Gutzwiller, 2008). For example, Aebi-Müller acknowledges that intellectual abilities alone are insufficient and that a stable emotionality is crucial. She even grants the patient a right to self-determination where she is no longer in full possession of her cognitive faculties but her decisions are based on solid emotional grounds.

5.2 Risk-Relativity

What role should the consequences of a decision play in the evaluation of a patient's decision-making capacity? This question has occupied researchers ever since conceptual analyses first gathered momentum in the 1980s. Obviously, it seems appropriate to scrutinize decision-making capacity more thoroughly where the consequences are severe. However, consequences are also seen to play another role. Drane (1985) was one of the first to suggest a *sliding-scale model* of competence that proposes variable standards for decision-making capacity, depending on the consequences entailed by a decision. More specifically, it proposes that the more severe the consequences, the more stringent are the standards of mental abilities necessary to deem a patient competent.

Drane (1985) elaborated a framework involving three general categories of medical situation, characterized by differences in objective risk-benefit ratios, certainty indexes, and available alternative treatments. The least stringent standard for competence applies in

instances where the patient chooses a treatment alternative that is safe, effective, and objectively in the patient's best interest. A patient's "awareness" (in the sense of being in contact with one's situation) and "assent" meet these minimal requirements. The second category captures treatment decisions that are more dangerous, less effective, more uncertain with regard to diagnosis or treatment, or involving different alternatives with balanced risks and benefits. In these instances, Drane proposes "understanding" and "evidencing a choice" as adequate standards for competence. Finally, the most stringent standard applies to treatment decisions that are very dangerous and run counter to professional and public rationality. Such decisions are to be respected if the patient satisfies the most demanding standard for competence, which, according to Drane, is "appreciation" and "reasoning", or the ability to fully grasp the situation technically, personally, intellectually, and emotionally, giving reasons for the choice and relating it to one's personal values. Risk-relative evaluations of competence are viewed as warranted because they allow an appropriate balance to be struck between the moral principles of autonomy and beneficence (Buchanan & Brock, 1989; Drane, 1985; Grisso & Appelbaum, 1998a). As Drane (1985, p. 21) notes: „A balancing of values is the cornerstone of a good competency assessment." As determining a patient's decision-making capacity requires judgment of whether or not their mental abilities are sufficiently intact, relevant thresholds must be defined. Proponents of risk-relativity argue that the determination of meaningful thresholds is achieved only by due consideration of the prevailing values of patient self-determination and well-being (Brock, 1991). In this respect, the consequences of a decision are crucial—for example, Grisso and Appelbaum (1998a) propose a so-called *competence balance scale* to illustrate how a final judgment of competence is arrived at, in which one side or cup of the scale represents the principle of autonomy and the other represents the principle of beneficence or patient protection. Insights into patients' decision-making abilities are placed in the *autonomy cup*; the better the abilities, the more the cup is loaded, favoring respect for the patient's self-determination. On the other side, the *protection cup* is filled with information pertaining to the potential consequences of a patient's choice. The less favorable the risk-benefit ratio, the more weight is given to patient protection. In other words, serious consequences require better mental abilities to keep the scale tipped toward autonomy. In general, „The judgment will be for competence, if the interest in respecting the patient's autonomy finally outweighs the interest in protecting the patient from the potentially harmful consequences of his or her decision-making incapacities. It will be for

incompetence, if the interest in protecting outweighs autonomy." (Grisso & Appelbaum, 1998a, p. 130)

According to Brock (1991), risk-relativity needs to be viewed in the broader context of the doctrine of informed consent and the function of competence determinations. The central function of any determination of competence is to allocate decisional authority, sorting people into two classes: those patients whose choices must be respected (favoring self-determination) and those whose choices are set aside and for whom others will decide (favoring patient well-being). This intricate default connection in the legal doctrine between (in)competence and decisional authority makes it impossible to judge decision-making capacity independently of the balancing of moral principles or considerations of justified paternalism (Brock, 1991), and will be further examined in subsequent sections. For the moment, it suffices to state that there are good reasons for evaluating decision-making capacity risk-relatively. Many scholars and most authoritative sources acknowledge that consequences matter in competence judgments while at the same time holding that, without due consideration of the patient's decision-making process, outcome alone can never justify a judgment of incompetence (Brock, 1991; Buchanan & Brock, 1989; Grisso & Appelbaum, 1998a; Kim, 2010).[21] Others look less favorably on risk-relativity, viewing it as opening the door to unwarranted paternalism.

5.2.1 Objection: Disguised Unwarranted Paternalism

Opponents of risk-relativity maintain that if incompetence is a necessary condition for setting aside a patient's wishes, there must be a finding of incompetence that is independent of the judgment that paternalism is justified (e.g., Cox White, 1994; Wicclair, 1991b). If not, deep rooted ethical disagreements about the moral obligations pertaining in a particular situation (either to respect patients' decisions or to protect them) would be wrongfully shifted into a disagreement about patients' decision-making capacity (Wicclair, 1991b), and standards relating to mental abilities would be set arbitrarily or unattainably high by those who believe that paternalism is justified by severity of consequences (Cale, 1999; Wicclair, 1991b). In short, risk-relativity is seen here as a means of disrespecting a patient's unwise and irrational choices, representing the kind of camouflaged *outcome standard* for competence that is unanimously rejected.[22] Opponents of risk-relativity do not

[21] See section 4.3.

[22] See section 4.3.

believe it to be reconcilable with a process-oriented understanding of decision-making capacity (Wicclair, 1991a).

In summary, while proponents of risk-relativity claim that consideration of risk is essential for meaningful, appropriate, and responsible judgments of competence and is compatible with a process-oriented approach, opponents see risk-related standards as evolving from bad intentions, allowing unwarranted medical paternalism to be introduced through the back door.

5.2.2 Objection: Asymmetrical Competence

The same scholars who are concerned about the danger of unwarranted paternalism often raise another argument against risk-relativity. If risk-relativity is taken seriously, it may happen that a patient is deemed competent to consent but incompetent to refuse treatment because consent and refusal entail different risks. Opponents regard such asymmetrical constellations as paradoxical and counterintuitive because the same mental abilities can indicate in one context (treatment consent) competence and in another context (treatment refusal) incompetence (Cale, 1999; Wicclair, 1991b; 1999). Obviously, this is a disturbing paradox if competence is conceived as an intrinsic feature of a person—understood as the ability to make a decision analogous to the ability to ride a bike (Kim, 2010). However, others judge asymmetrical competence unproblematic (Kim, 2010; Wilks, 1997). Could it be then that different conceptions of decision-making capacity exist and underly the debate on risk-relativity? This question will be further examined in subsequent chapters.

5.2.3 Empirical Evidence for Risk-Relative Evaluations

There is little empirical evidence regarding the use of risk-relative standards. However, an experimental study by Kim, Caine, Swan, and Appelbaum (2006) showed that risk does indeed impact on the thresholds used by clinicians to determine decision-making capacity. Moreover they could demonstrate that there is substantial variability in judgments among evaluators that cannot be fully explained by risk perception, indicating the possibility of other factors that predict variability in standards, including the evalutor's individuality. Of particular interest in this regard are evaluators' weighting of autonomy in relation to welfare considerations and their personal values. In a brief follow-up inquiry, the authors established that the study participants varied in their preferences for autonomy and welfare, although no effect on competence judgments could be demonstrated (Kim, 2010).

In this light, further investigation of personal biases in evaluations of competence seems worthwhile.

5.3 Evaluation Procedure and Standardization

A third area that has attracted considerable attention in the literature concerns procedures and the role of standardization in competence evaluations. Clearly, such considerations are intimately connected to the aformentioned discussions regarding criteria and risk-relativity. To qualify as an evaluator of competence requires insight into the concept of decision-making capacity as well as knowledge of the processes involved in arriving at a competence judgment. To this end, several guides have been developed for clinicians, of which the most prominent is that of Grisso and Appelbaum (1998a).[23] In broad terms, these guides distinguish between descriptive assessment of relevant information (about patients' mental abilities and contextual factors) and the integration of this information into a final categorical judgment of competence or incompetence.

5.3.1 Relevant Information

According to Grisso and Appelbaum (1998a), there are four sorts of information that should be assessed in competence evaluations: (1) the patient's psychopathological status; (2) those mental abilities regarded as relevant for competence (e.g., *understanding, appreciation, reasoning, expressing a choice*); (3) the situational demands on the patient's abilities (e.g., complexity of the information or other factors that make the decision-making task more or less difficult); and (4) the probable consequences of the patient's treatment choice.

Assessment of a patient's psychopathology is relevant because such symptoms may substantially influence the mental abilities relevant for competence (Grisso & Appelbaum, 1998a) and provide the objective causes required in Swiss law to deem a patient incompetent. It is also important to assess decisional demands because, again, these interact with a patient's decision-making performance. Moreover, identification of performance-undermining contextual factors allows effective intervention to overcome hurdles, thereby supporting and promoting patient decision making (Grisso & Appelbaum, 1998a). Finally, assessment of the risk-benefit profile of a decision is crucial if competence is risk-relatively evaluated.

[23] See also Kim (2010), Cox White (1994), and American Bar Association (2008).

5.3.2 Standardized Assessment Tools

Specific tools have been developed for the assessment of relevant decision-making capacities in relation to treatment decisions. In a comprehensive review of these instruments, Lamont and colleagues (2013a) showed how they differ with regard to format (structured or semi-structured interview), subject (hypothetical vignette or actual treatment decision), assessed domain (*understanding, appreciation, reasoning, expressing a choice*), administration time, required assessment skills, psychometric properties, and standardization sample. Overall, they concluded that only a few tools have been found to have both reliablity and validity. Of these, only the *MacArthur Competence Assessment Tool For Treatment* (*MacCAT-T*; Grisso & Appelbaum, 1998b) is available as a published manual. These observations tend to support the assumption that most of these tools have been developed primarily for selective research purposes rather than to inform the assessment practice of clinicians (Kim, Karlawish, & Caine, 2002).

The MacCAT-T is a semi-structured interview that purports to assess *understanding, appreciation, reasoning,* and *expressing a choice* with regard to an actual treatment decision, combining assessment with the informed consent procedure. It consists of three steps: (1) *preparation*, (2) *interview*, and (3) *rating*. Prior to meeting with the patient, the clinician obtains and organizes information (on the MacCAT-T Record Form) that will be disclosed later, during the interview. The relevant information pertains to the *diagnosis of disorder, features of disorder, course of disorder, recommended treatment, features of recommended treatment, benefits/risks of recommended treatment,* and *alternative treatments.* In the interview, the information is disclosed step by step, in combination with inquiries into the patient's mental abilities. As the patient is questioned, his or her responses are recorded on a form, with further probing as necessary, according to the instructions provided in the interview guide. After the interview, the patient's responses are used to rate their abilities, which are precisely operationalized in a rating scheme that assigns scores between 0 and 2 to each item. Instructions for summary ratings are provided for *understanding, appreciation,* and *reasoning.* Approximately 30 minutes are required to administer the MacCAT-T (inclusive of preparation and rating).

5.3.3 Integrating Information into a Final Judgment

In the MacCAT-T manual, it is repeatedly stated that no interview score can be directly translated into a judgment of competence or incompetence: „No particular level of ability is always associated with competence or incompetence across all patients, all disorders, and

all medical situations“ (Grisso & Appelbaum, 1998b, p. 23). On that basis, no cut-off scores can be derived from the results of the MacCAT-T. Rather, it is necessary to interpret these results, to put them into context, and to relate them to other clinical observations derived from diagnostic assessment, psychopathologial status examination, the patient‘s psychiatric or psychosocial history, or aspects of the specific decision. Building on the integration of these data, the final judgment is necessarily normative. Grisso and Appelbaum (1998a, p. 130) frame the relevant question as follows: „Does this patient have sufficient ability to make a meaningful decision, given the circumstances with which he or she is faced?“ This still more telling question could be formulated if the function of competence determinations in the doctrine of informed consent were considered: *Ought the patient to retain decisional authority, given his or her decision-making capacities and the circumstances with which he or she is faced?*

Translating measurements of abilities into a dichotomous judgment is a difficult task in any competence evaluation, to which no algorithms can be applied (Grisso & Appelbaum, 1998a; Kim, 2010). According to Kim (2010), there are potentially different approaches to determining thresholds to indicate whether or not the patient's abilities are sufficient for competence. First, cut-offs could be determined *a priori*, perhaps on the basis of theoretical reflections. Second, *statistical* thresholds could apply that grounding to psychometrical analyses, perhaps mark individuals who score two standard deviations below the mean on mental abilities as incompetent. Both of these options face the same problem: cut-offs do not sufficiently reflect societal values and therefore have no intrinsic ethical meaning (Kim, 2010). Because they seem to exist in a vacuum, they appear unduly arbitrary. The third alternative that might remedy this drawback is an *expert judgment* threshold, grounded on a balancing of moral principles or on consideration of the risk-benefit context. This brings us back to the significance, or even necessity, of risk-relativity in competence evaluations. The mental picture of a *competence balance scale,* as introduced in the context of risk-relativity,[24] is Grisso and Appelbaum's response to what is involved in the process of reaching a competence judgment.

[24] See section 5.2.

5.3.4 Value of Standardization

Standarization can help to improve the reliability and validity of assessments of patients' decision-making capacities.[25] Instruments force the evaluator to be comprehensive and so ensure that relevant information is assessed. Moreover, interview forms allow patients' perfomance to be documented in a systematic way (Kim, 2010). However, despite these advantages, standardization of competence evaluations may also have considerable drawbacks, which include the following.

First, criticism of the traditional approach has indicated that the operationalizations of mental abilities in the MacCAT-T fail to take proper account of emotional or valuational components despite acknowledgment of such elements by the instrument's developers. Could it be, then, that standardized procedures override the nuanced influence of emotions and values because of difficulties in operationalizing them? And might a sensitive assessment of emotional and valuational processes be further undermined by standardization itself, by virtue of an unavoidable mechanistic, formulaic, or perhaps overly analytical element in the assessment?

The second concern does not directly pertain to standardization but more to one of its critical side effects. Although it is recognized in the research literature that instruments only quantify mental abilities and do not allow direct inference of a competence judgment, the descriptive assessment of mental abilities occupies a very prominent position by comparison with the core (and perhaps most challenging) aspect of competence determinations: translation into a clinical judgment. As a result, the essential normative dimension fades into the background, ultimately conveying a misleading picture of the nature of competence as an overly descriptive construct. These concerns are further elaborated in the sections that follow.

6 Layers of Normativity

The preceding sections have introduced diverse aspects of the concept of decision-making capacity, raising questions about normativity and the import of values in a number of ways. For conceptual clarity, it is worth disentangling these different layers for subsequent integration into an overall picture of competence. The significance of decision-making

[25] However, in general the reliability and validity of instruments is insufficiently examined (the MacCAT-T is an exception) (Lamont et al., 2013a; Sturman, 2005). A particular difficulty is the lack of a real gold standard serving as a generally acccepted criterion validity standard (Moye et al., 2006).

capacity as a gatekeeper in the doctrine of informed consent has been explicated in the outline of the ethical and legal foundations: patients' (in)competence determines whether or not they are granted a right to self-determination, or whether patient autonomy or patient welfare is given priority. It follows that *competence is ethically relevant* because it determines how moral principles are to be balanced.

Second, in the context of risk-relativity and the determination of meaningful thresholds (that is, the translation of descriptive data into a dichotomous judgment), the balancing of moral principles proves essential. In other words, *ethical considerations involving a weighting of moral values are constitutive of decision-making capacity*. In combination, these two layers obviously entail a circular argument, and concerns about their compatibility may arise.

Third, normative considerations are also involved in *determining and specifying relevant criteria for competence*. In the first place, this seems to be a non-ethical normative matter. However, in light of the aforementioned layers of normativity, this assumption requires further scrutiny; it is hardly imaginable that the overarching moral frame does not affect the selection of relevant standards in relation to mental abilities. This claim finds support from a fourth layer of normativity relating to *substantive criteria for competence*, implying an external value judgment on the part of the evaluator. Moral intuitions are seen to underpin the requirement for substantive criteria as well as related specific value judgments (Freyenhagen & O'Shea, 2013; Holroyd, 2012).

In general, the distinction between non-ethically and ethically normative considerations in defining decision-making capacity seems crucial and aligns with different conceptions of competence as either a construct that is *independent of a balancing of moral principles* or a construct that is *constituted by and therefore inherently reliant on a balancing of moral values*. The appropriateness of risk-relativity and substantivism, as well as the manner in which criteria and thresholds are determined, hinges on this dinstinction; criteria and thresholds can also be conceived as either *non-ethical* or *ethical*.

7 Publications

The preceding elaboration of controversies and challenges arising from the concept and the evaluation of decision-making capacity has three overarching themes: (1) *normativity;* (2) *criteria;* and (3) *assessment.* These themes are intimately connected to the extent that insights in one area necessarily have implications for the others. The articles that have been published in relation to this thesis approach these themes in various ways (either

empirically or theoretically), with differing emphases on single aspects (see Figure 1). Together, they are intended to promote a more integral understanding of decision-making capacity that can eventually support and enhance appropriate evaluations of competence in clinical practice.

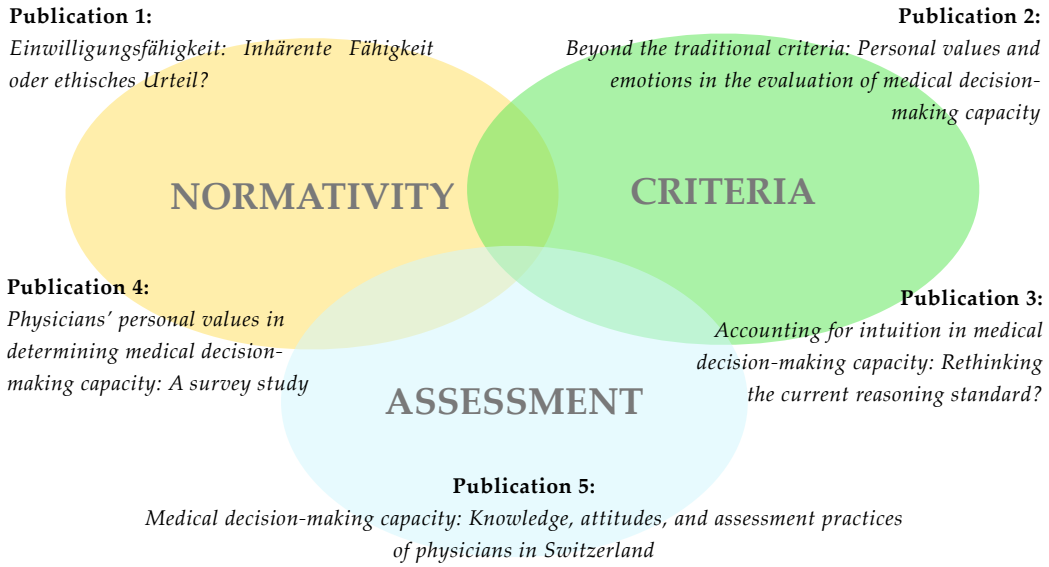

Figure 1. Themes and publications.

The first paper highlights basic conceptual issues, analyzing assessment of competence as either an *inherent ability* or an *ethical judgment* and so tackling the various understandings of how competence relates to moral values. It further explicates these positions and associated problems, drawing conclusions about the appropriateness of risk-relativity, the handling of criteria, and the evaluation process.

The second and third papers are primarily concerned with criteria addressing the associated criticisms. A literature review of the arguments for stronger recognition of emotional and valuational elements is accompanied by a general appraisal of emotions and values within competence determinations, including consideration of the assessment procedure. A separate paper deals in detail with the role of intuition in decision-making capacity and the need to take proper account of patients' decision-making styles, calling

into question the *reasoning* standard, its operationalization, and the adequacy of standardization, and favoring a more open, narrative approach.

A fourth paper investigates the role of clinicians' personal values in competence determinations from an empirical perspective, especially with regard to the use of risk-relative standards. It raises awareness of implicit personal biases and alludes to the problem of unwarranted and disguised paternalism.

The final paper is again empirical, reporting the results of a survey study conducted with physicians in Switzerland. It investigates physicians' knowledge, attitudes, and assessment practices in relation to decision-making capacity, providing an understanding of how the three themes are actually conceived by clinicians.

7.1 Einwilligungsfähigkeit: Inhärente Fähigkeit oder ethisches Urteil?

Helena Hermann, Manuel Trachsel, and Nikola Biller-Andorno (2015).
Einwilligungsfähigkeit: Inhärente Fähigkeit oder ethisches Urteil? *Ethik in der Medizin*, doi: 10.1007/s00481-015-0360-x.

Zusammenfassung:

Die Bestimmung der Einwilligungsfähigkeit von Patienten beinhaltet weitreichende ethische und rechtliche Implikationen. Ausreichende Klärung des Begriffs ist daher unerlässlich. Solche Bemühungen gelten vorwiegend der Definition von Kriterien hinsichtlich relevanter mentaler Fähigkeiten. Grundlegendere Aspekte werden kaum explizit besprochen, so die Frage, ob Einwilligungsfähigkeit eher eine inhärente Fähigkeit oder ein ethisches Urteil bezeichnet. Zentral bei dieser Unterscheidung ist der Stellenwert ethischer Überlegungen die Zulässigkeit fürsorglicher Bevormundung betreffend. Geht man von einer inhärenten Fähigkeit aus, schließen solche Überlegungen an die Beurteilung von Einwilligungsfähigkeit an. Im Fall eines Urteils sind diese konstitutiv für das Verständnis und die Bestimmung von Einwilligungsfähigkeit. Obwohl Einwilligungsfähigkeit idealerweise als inhärente Fähigkeit gedacht wird, weist die tatsächliche Herangehensweise eher in die Richtung, sie als ethisches Urteil zu verstehen. Diese verschiedenen Tendenzen sind für konzeptuelle Kontroversen hinsichtlich des Stellenwerts risiko-relativer Beurteilungen verantwortlich. Des Weiteren muss sich die Bestimmung von Einwilligungsfähigkeit—konzipiert man sie als ethisches Urteil—nicht rigide an einer bestimmten Definition des Begriffs der Autonomiefähigkeit orientieren und vermag so mit dessen definitorischen Unklarheiten besser umzugehen.

Als Voraussetzung für die informierte Einwilligung in eine medizinische Intervention kommt der Einwilligungsfähigkeit (EF)[26] des Patienten eine wichtige Rolle zu. Sie bestimmt, ob von einer gültigen Patienteneinwilligung ausgegangen werden kann und inwieweit der Patientenselbstbestimmung Geltung und Respekt zukommt. Diese ethischen und rechtlichen Implikationen verlangen nach einer angemessenen und sorgfältigen Beurteilung der EF in der klinischen Praxis.

In der Auseinandersetzung mit dem Konzept der EF zeigt sich bald dessen Komplexität und man sieht sich mit grundlegenden Fragen konfrontiert: Worum geht es bei der Beurteilung von EF und wofür ist der Begriff bezeichnend? Diese Fragen bezwecken eher ein grundlegendes Verständnis, als die Definition konkreter, inhaltlicher Aspekte wie die Bestimmung relevanter mentaler Fähigkeiten.[27] Oftmals sind Letztere Gegenstand ausführlicher Reflexionen, ohne dass aber ausreichend Klarheit betreffend elementarerer Punkte bestehen würde. So entsteht beim Lesen der Literatur der Eindruck, es gäbe unterschiedliche Vorstellungen darüber, was EF grundsätzlich bezeichnet. Manche verstehen sie als inhärente Fähigkeit des Patienten (z.B. Wicclair, 1991b), andere als ein ethisches Urteil (z.B. Buchanan & Brock, 1989). Es handelt sich um verschiedene Betrachtungsweisen mit je unterschiedlichen Vorstellungen des normativen Gehalts von EF; es sind Divergenzen, die beispielsweise der Debatte um risiko-relative Beurteilungen von EF zugrunde liegen und dort besonders prägnant zu Tage treten (vgl. Brock, 1991; Wicclair, 1991b).[28] Eine Klärung der Frage, was mit EF grundsätzlich gemeint wird, ist ausstehend. Der vorliegende Beitrag hat daher das Ziel, diese unterschiedlichen Vorstellungen von EF genauer zu untersuchen.

Einwilligungsfähigkeit im Kontext der *informierten Einwilligung*

Es bietet sich an, die beiden Konzeptionen von EF—einerseits als inhärente Fähigkeit, andererseits als ethisches Urteil—vor dem Hintergrund der *informierten Einwilligung* einzuführen. Die *informierte Einwilligung* macht das Recht des Patienten auf Selbstbestimmung geltend. Sie entwickelte sich in der Mitte des 20. Jahrhunderts aus gesellschaftlichen Tendenzen und liberalen Strömungen sowie der Aufdeckung schwerer Missbrauchsfälle in

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[26] Im schweizerischen Recht gilt der Begriff der Urteilsfähigkeit (Schweizerisches Zivilgesetzbuch, Art. 16).

[27] Gängige Kriterien in Anlehnung an Grisso und Appelbaum (1998a) sind: Informationsverständnis (*understanding*), Krankheits- und Behandlungseinsicht (*appreciation*), Gewichtung und Integration von Informationen (*reasoning*), Kommunikation eines Entscheids (*evidencing a choice*).

[28] Die Debatte wird auch unter dem Stichwort *Sliding Scale* geführt (z.B. Drane, 1985). *Risiko-Relativität* und der Begriff *Sliding-Scale* verweisen beide auf eine Beurteilung der EF in Abhängigkeit der Konsequenzen eines Entscheids.

der klinischen Forschung. Beides führt zu einer Aufwertung der Patientenselbstbestimmung und einer Infragestellung der traditionellen ärztlichen Ethik, nach der ein tugendhafter Arzt alleine zum Wohl des Patienten entscheidet (Faden & Beauchamp, 1986). Grundsätzlich gilt, dass vor jeder medizinischen Intervention eine ausdrückliche Einwilligung des Patienten eingeholt werden muss. Von einer gültigen Einwilligung oder einem gültigen Behandlungsverzicht ist jedoch nur dann die Rede, wenn die folgenden Bedingungen erfüllt sind: 1) Der Patient ist ausreichend informiert; 2) versteht die vermittelten Informationen; 3) trifft die Entscheidung freiwillig; und 4) besitzt EF (Faden & Beauchamp, 1986). Unter diesen Bedingungen gilt es, den Entscheid des Patienten zu respektieren, auch wenn dieser mit schädlichen Folgen, gar dem Tod einhergeht. Sind diese Voraussetzungen hingegen nicht erfüllt, ist der Respekt vor dem Entscheid des Patienten nicht geboten. Andere moralische Prinzipien, wie der Schutz des Patienten, können dann Vorrang haben (Buchanan & Brock, 1989). So entsteht der Eindruck, dass in der Ausformulierung der *informierten Einwilligung* die volle Entscheidungshoheit des Patienten durch die genannten Voraussetzungen eine Restriktion erfährt. Eine solche Restriktion ist plausibel und lässt sich aus zweierlei Perspektive erklären. Im einen Fall wird die Selbstbestimmung des Patienten als Erklärung in den Vordergrund gestellt, im anderen Fall sind es paternalistische Überlegungen, die im Fokus stehen. Wenn nun im Folgenden diese zwei Perspektiven genauer betrachtet werden, soll dies lediglich im Hinblick auf die vierte Bedingung der *informierten Einwilligung*, die EF, geschehen.

Argumentiert man ausgehend von der Selbstbestimmung, kommt dem Patienten nur dann ein Recht auf Achtung seines Entscheids oder seiner Selbstbestimmung zu, wenn er auch fähig ist, sich selbst zu bestimmen. Zudem ist dieses Recht im Kontext der *informierten Einwilligung* unter dieser Voraussetzung ein absolutes (Buchanan & Brock, 1989). Diese Fähigkeit zur Selbstbestimmung als Bedingung für eine gültige Einwilligung wird unter dem Begriff der EF gefasst. Folglich wird EF als eine inhärente Fähigkeit des Patienten oder spezifischer als ein Komplex mentaler Fähigkeiten verstanden. Als eine solche ist sie unabhängig von ethischen Überlegungen, welche die Angemessenheit paternalistischer Maßnahmen betreffen. Hingegen bestimmt sie als Voraussetzung für eine gültige Einwilligung, ob fürsorgliches Fremdbestimmen erlaubt oder gar geboten ist.

Der Stellenwert der EF innerhalb der *informierten Einwilligung* lässt sich jedoch nicht nur von der Warte der Selbstbestimmung betrachten, sondern auch aus der Perspektive paternalistischer Bevormundung. Mit dem noblen Zweck der *informierten Einwilligung*, unzulässigen Paternalismus einzudämmen, muss, ohne die genannten Voraussetzungen, in

Kauf genommen werden, dass alle Interventionen Dritter—sowohl unzulässiger als auch moralisch zulässiger Paternalismus—unrechtmäßig sind. Um diesem unerwünschten Effekt entgegenzuwirken, braucht es die genannten Voraussetzungen der *informierten Einwilligung*. EF kann so als Mittel gesehen werden, gerechtfertigtem Paternalismus wieder den Weg zu ebnen. Pointierter ausgedrückt, beschreibt und umfasst die Kategorie *Einwilligungsunfähigkeit* all jene Individuen, bei denen man zu der Überzeugung gelangt, dass eine Bevormundung aufgrund von Faktoren, die innerhalb der Person liegen, legitim oder gar geboten ist. Diese Herangehensweise bringt mit sich, dass EF nicht primär als eine inhärente Fähigkeit verstanden wird, sondern als zweckdienliches Etikett, das jene Personen umfasst, bei denen man eine fürsorgliche Fremdbestimmung als moralisch richtig erachtet. Aus diesem Verständnis folgt, dass die Bestimmung von EF eng mit ethischen Überlegungen betreffend gerechtfertigten respektive ungerechtfertigten Paternalismus verknüpft ist.[29] EF ist somit keine unabhängige Voraussetzung für paternalistisches Eingreifen, sondern ein aus diesen ethischen Überlegungen heraus konstruierter Begriff.

Hier treffen zwei Perspektiven aufeinander, die sich hinsichtlich ihrer Ausgangslage voneinander unterscheiden, was folgende Fragen aufwirft: Besteht in der Begegnung mit bestimmten Patienten zuerst die moralische Intuition, dass diesen aufgrund gewisser Merkmale schützend beigestanden werden muss? Veranlasst diese Intuition dazu, über ihre Ursachen nachzudenken, diese zu systematisieren und unter den Begriff der EF zusammenzufassen? Oder steht die Vorstellung eines selbstbestimmten Individuums am Anfang, von der bestimmte Patienten derart abweichen, dass es ihnen unmöglich ist, selbstbestimmt zu entscheiden, weshalb schützende Maßnahmen geboten sind?—Der wesentliche Unterschied zwischen den beiden Betrachtungsweisen liegt dort, wo es um ein Gewichten moralischer Prinzipien geht. Im einen Fall basiert die Bestimmung von EF auf einem Abwägen moralischer Grundsätze. Im anderen Fall erfolgt dieses Abwägen erst im Anschluss an die Beurteilung der EF, wobei die EF darüber bestimmt, wie die Prinzipien zu gewichten sind. Es stellt sich die Frage, welches der beiden Modelle bevorzugt wird. Es wäre nicht erstaunlich, würde die Mehrheit auf das zweite Modell setzen, da es in sich schlüssig und im Vergleich zum ersten Modell weniger widersprüchlich erscheint, denn jenes weist im

[29] In der Literatur finden die Begriffe schwacher und starker Paternalismus Verwendung, um gerechtfertigtere und ungerechtfertigere Formen von Paternalismus zu unterscheiden (siehe Feinberg, 1971). Schwacher Paternalismus bezeichnet fürsorgliche Maßnahmen in Fällen unzureichend autonomer Entscheidungen, beispielsweise bei fehlender EF, und gilt als moralisch unproblematisch. Starker Paternalismus hingegen steht für fürsorgliche Fremdbestimmung bei einer hinreichend autonomen Entscheidung des Patienten, und ist aus moralischer Perspektive umstritten. Auf die Verwendung dieser Begriffe wird in der vorliegenden Arbeit verzichtet, weil sie bereits ein Verständnis von EF als inhärente Fähigkeit implizieren und deshalb für die Infragestellung eines solchen nicht geeignet sind.

Kontext der *informierten Einwilligung* tatsächlich eine gewisse Zirkularität auf. Es wird hier behauptet, dass die Idee einer inhärenten Fähigkeit zwar einer Idealvorstellung entspricht, dass EF sinnvollerweise aber als ethisches Urteil angegangen wird. In den folgenden Abschnitten werden Gründe und Evidenzen für diese Behauptung vorgebracht.

Bestimmung von Grenzwerten

Es ist anerkannt, dass die Bestimmung von EF eine normative Angelegenheit ist (Berghmans et al., 2004). Sie lässt sich nicht direkt aus der Deskription von Patientenmerkmalen ableiten, sondern verlangt ein Urteil darüber, ob diese Merkmale, die meistens in Abstufungen vorliegen, ausreichend intakt sind. Nur durch die Bestimmung solcher Grenzwerte kommt man zu einem dichotomen Urteil (*einwilligungsfähig* oder *einwilligungsunfähig*) (Buchanan & Brock, 1989).

Grenzwerte lassen sich auf unterschiedlicher Basis festlegen. Es wäre möglich, sie a priori aus theoretischen Überlegungen abzuleiten, aus Reflexionen darüber, was Selbstbestimmungsfähigkeit bedeutet. Die tatsächliche Vorgehensweise ist jedoch eine andere. Namhafte Autoren betonen, dass das Festlegen von Grenzwerten einzelfallspezifisch auf einem Abwägen moralischer Prinzipien beruht, genauer auf dem Prinzip des Patientenschutzes einerseits und des Respekts vor dessen Selbstbestimmung andererseits (Brock, 1991; Buchanan & Brock, 1989; Faden & Beauchamp, 1986; Grisso & Appelbaum, 1998a). So schreibt Brock (1991, S. 106):

> *Suppose that we are correct that the central function of the competence determination is to allocate decisional authority either to the patient or to surrogate. Why does the competence determination then require balancing patients' self-determination and well-being? The answer is that these are the two fundamental interests or values of patients which are at stake in whether they retain decisional authority about their medical treatment.*

Weiter sagt er:

> *[...] the crucial question on a particular occasion for competence is how good decisionmaking must be to be "good enough" to warrant leaving decisional authority with the patient and respecting his or her choice. It is in answering this question in borderline cases that balancing the patient's self-determination and well-being is required* (Brock, 1991, S. 106).

Den Zitaten zufolge spielt das Abwägen moralischer Prinzipien eine zentrale Rolle bei der Definition von Grenzwerten, die letztlich über die EF bestimmen. Es handelt sich um eine ethisch normative Aufgabe, womit eine Parallele zum Denkmodell besteht, das EF als ethisches Urteil konzipiert und moralischen Intuitionen eine wichtige Rolle zuweist.

Eine solche Vorgehensweise ist mit risiko-relativen Standards gekoppelt, denn sie schließt Merkmale der Entscheidungssituation inklusive der Folgen einer Entscheidung ein; diese geben dem Prinzip des Patientenschutzes Gewicht. Eine derartige Bestimmung von Grenzwerten ist also sowohl theoretisch gestützt, als auch durch die vorherrschende Rechtspraxis, welche EF risiko-relativ beurteilt, als lege artis anerkannt (Nedopil et al., 2012).

Bedeutung moralischer Intuitionen

Die Art und Weise wie in der Literatur die gängigen Kriterien für EF diskutiert werden, bestätigt EF ebenfalls als ethisches Urteil. Mehrere Beiträge legen ihre Argumentation um illustrative Fälle herum an (Banner, 2012; Halpern, 2012; Tan, Stewart, Fitzpatrick, & Hope, 2006). Dabei werden Personen beschrieben, die man intuitiv zu ihrem Wohl schützen würde. Die Autoren setzen also bei den moralischen Intuitionen der Leser an, um dann zu zeigen, dass unter den gegenwärtigen Kriterien für EF, genau dort, wo paternalistische Maßnahmen angebracht wären, die Patienten entgegen der intuitiven Einschätzung einwilligungsfähig sind. Im Anschluss wird die Essenz dieser Intuitionen herausgearbeitet und Argumente für eine Revision der gängigen Kriterien vorgelegt. Obwohl die Selbstbestimmungsfähigkeit des Patienten von den Autoren als Begründung herangezogen wird, bleibt der Ausgangspunkt für die Überarbeitung des Konzepts der EF die intuitive Einschätzung darüber, ob fürsorgliches Fremdbestimmen im konkreten Fall gerechtfertigt ist. Moralische Intuitionen, die im Grunde ein implizites Abwägen moralischer Prinzipien bedeuten, spielen in der Konzeption von EF somit eine zentrale Rolle (Holroyd, 2012).

Noch deutlicher zeigt sich dies dort, wo stabile moralische Intuitionen vorliegen, es jedoch Schwierigkeiten bereitet, diese zu systematisieren, durch universelle Kriterien abzubilden oder mit einem wertneutralen Verständnis von Autonomie in Einklang zu bringen. Ein Beispiel hierfür ergibt sich aus dem Vergleich eines Behandlungsverzichts aufgrund religiöser Gründe und aufgrund von Wahnvorstellungen (vgl. Radoilska, 2012a). In beiden Fällen erfolgt der Verzicht mit gutem Informationsverständnis und einer kohärenten Argumentation. Das Mitglied einer Sekte begründet seinen Entscheid damit, dass der medizinische Eingriff sein Verhältnis zu Gott nachhaltig beeinträchtige, während der Psychotiker der Überzeugung ist, dass durch den Eingriff seine Verbindung zu außerirdischen Unionen auf dem Spiel stehe. Die Existenz Gottes oder außerirdischer Unionen sowie deren Verhältnis zum Patienten sind gleichermaßen evident wie

unrealistisch. Es ist also schwierig, diese beiden Patienten zu unterscheiden, außer man hebt das wertneutrale Verständnis von Autonomie auf und bezieht eine klare normative Position für oder gegen den Glauben an Gott oder außerirdische Unionen. Möchte man hingegen die Wertneutralität aufrechterhalten, müssen entweder beide als einwilligungsfähig oder beide als einwillig*un*gsunfähig bezeichnen werden. Dies entspricht jedoch nicht der gängigen Intuition, derzufolge die Patienten nicht gleich zu behandeln sind. Im Falle des religiösen Patienten besteht weitgehender Konsens, seinen Entscheid zu respektieren—man denke nur an die Verweigerung von Bluttransfusionen bei einem Zeugen Jehovas (Beauchamp & Childress, 2009); im Falle des Psychotikers wird paternalistisches Intervenieren hingegen als zulässig erachtet.

Formuliert man, was diesen unterschiedlichen Intuitionen zugrunde liegt, lassen sich unterschiedliche Punkte anführen. Im Falle des Psychotikers kann argumentiert werden, dass der Wahn Ausdruck einer psychischen Erkrankung ist und der Entscheid somit nicht das wahre Selbst des Patienten widerspiegelt, also nicht authentisch ist. Womöglich spielt es auch eine Rolle, dass der Wahn des Psychotikers höchst individualisiert ist, während die Vorstellungen des religiösen Patienten von einer größeren Gemeinschaft geteilt werden. Hinzu kommt die Tatsache, dass religiöse Praktiken in allen Kulturen verankert sind; dies gilt für den Glauben an außerirdische Unionen nicht. Entsprechend ist es wahrscheinlich, dass unserer Intuition auch ein explizites Werturteil zugrunde liegt. Solche Argumente stellen also nicht nur ein wertneutrales Verständnis von Autonomie auf die Probe, sondern sind schwer als allgemeingültige Kriterien zu formulieren. Würde man beispielsweise die Authentizität eines Entscheids zu einem solchen Kriterium machen, ergäben sich andere Schwierigkeiten: Man stelle sich zum Beispiel vor, der religiöse Patient ist erst eine Woche vor dem Behandlungsverzicht der Sekte beigetreten und hat sich davor noch nie zu einem religiösen Glauben bekannt. Kann man in diesem Fall von einem authentischen Entscheid sprechen? Und wenn ja, welches Verständnis von Authentizität legen wir zugrunde? Sollte es Menschen nicht auch erlaubt sein, ihre Werthaltungen und Lebensführung radikal zu ändern?—Ein Argumentieren über die Authentizität funktioniert besonders gut im Zusammenhang mit psychiatrischen Diagnosen, die eine Trennung zwischen einem erkrankten, nicht-authentischen und einem gesunden, authentischen Selbst suggerieren.

Intuitionen hinsichtlich der EF verschiedener Patienten fallen unterschiedlich aus. Oft ist man zwar in der Lage, diese Intuitionen zu erklären und Argumente für oder gegen die EF vorzubringen. Diese Begründungen sind jedoch fallspezifisch; sie lassen sich nicht vollständig aus allgemeingültigen Kriterien für selbstbestimmtes Handeln ableiten. Ebenso ist

es oft schwierig, in solchen Fällen an einem wertneutralen Verständnis von Autonomie oder EF festzuhalten (Holroyd, 2012; Radoilska, 2012a). Um solche Schwierigkeiten zu umgehen, wird in der Literatur der Vorschlag diskutiert, die Frage nach der Zulässigkeit paternalistischer Interventionen unabhängig von der Frage nach der EF zu beantworten (Buchanan & Brock; Martin, 2007; Radoilska, 2012a; Wicclair, 1991b). Das bedeutet, dass fürsorglich eingegriffen werden kann, obwohl eine Person einwilligungsfähig ist, oder umgekehrt, dass ein Patientenentscheid trotz der Einwilligungs*un*fähigkeit des Patienten zu respektieren ist. Soll also—bezogen auf die obige Ausgangslage—der psychotische Patient als einwilligungs*un*fähig erklärt werden, gilt dies konsequenterweise auch für den religiösen Patienten; somit ist dieser ebenso einwilligungs*un*fähig, sein Entscheid aber dennoch zu respektieren. Soll umgekehrt der religiöse Patient als einwilligungsfähig beurteilt werden, was dann gleichermaßen für den psychotischen Patienten gilt, würde man urteilen, dass Letzterer zwar einwilligungsfähig ist, eine Bevormundung aber dennoch erlaubt ist. Dies veranschaulicht noch einmal, dass die Lösung im Grunde von Beginn an klar ist; das heißt paternalistisches Intervenieren ist gerechtfertigt im Falle des psychotischen Patienten und ungerechtfertigt im Falle des religiösen Patienten. Mühe bereitet das Formulieren von allgemeingültigen und wertneutralen Kriterien, sodass im beschriebenen Fall scheinbar nur noch auf eine Reformulierung des Verhältnisses von EF und moralisch Gebotenem zurückgegriffen werden kann (Holroyd, 2012).

Den Ausführungen zufolge bestehen also drei Möglichkeiten, das Verhältnis zwischen EF und moralisch Gebotenem zu konzipieren (vgl. Buchanan & Brock, 1989): 1) EF ist vollkommen losgelöst von ethischen Überlegungen; 2) EF ist von ethischen Überlegungen unbeeinflusst, bestimmt jedoch was moralisch geboten ist; 3) EF ist nicht unabhängig von ethischen Überlegungen beziehungsweise konstituiert sich teilweise über unsere moralischen Intuitionen und über ein Abwägen moralischer Prinzipien. Die zweite und dritte Konzeption finden sich in den beiden vorgeschlagenen Betrachtungsweisen von EF wieder. Die erste Konzeption macht im Kontext der *informierten Einwilligung* wenig Sinn; hat die EF keine bindenden Implikationen, wird sie ihrer Funktion als Voraussetzung für eine gültige Einwilligung, die ihrerseits bestimmt, ob der Patientenwille zu respektieren ist, nicht gerecht. Die Bestimmung der EF ist damit nutzlos und wird hinfällig (Brock, 1991; Buchanan & Brock, 1989).

Zwei Seiten einer Medaille?

In den vorhergehenden Abschnitten wurde bisher aufgezeigt, dass die tatsächliche Herangehensweise an das Konzept der EF, entgegen dem theoretischen Ideal, sie als inhärente Fähigkeit zu begreifen, in eine andere Richtung weist. Die Tatsache, dass sowohl die normative Bestimmung von Grenzwerten als auch die Infragestellung und Neuformulierung von Kriterien auf Intuitionen und Überlegungen basieren, die ein Gewichten moralischer Grundsätze beinhalten, spricht dafür, EF als ein ethisches Urteil zu verstehen. Es soll nun weiter untersucht werden, in welchem Verhältnis diese beiden Denkweisen zueinander stehen und welche praktischen und theoretischen Vorteile es hat, EF als ethisches Urteil zu denken.

Wie bereits dargelegt wurde, ist EF als inhärentes Merkmal eng mit dem Begriff der Selbstbestimmungsfähigkeit verbunden. Wenn man EF im Gegensatz dazu als Urteil versteht, resultiert sie aus einer situationsspezifischen Einschätzung der Angemessenheit paternalistischer Bevormundung. So gesehen ist EF das Ergebnis der Grenzziehung zwischen gerechtfertigtem und ungerechtfertigtem Paternalismus: Wird eine Bevormundung als legitim erachtet, besteht Einwilligungs*un*fähigkeit, und wo diese als ungerechtfertigt angesehen wird, besteht EF. Dabei wird die Bevormundung durch Merkmale des Patienten begründet.[30] Entsprechend lässt sich die Frage, deren Beantwortung Aufschluss über die EF gibt, wie folgt formulieren: Lässt sich paternalistisches Intervenieren durch Merkmale, die in der zu beurteilenden Person liegen, ausreichend rechtfertigen? Dem gegenüber steht die Frage, die im Zusammenhang mit der zweiten Konzeption zentral ist: Besitzt der Patient die Fähigkeit zur Selbstbestimmung? Es lohnt sich, diese Fragen genauer anzuschauen, insbesondere in ihrer Beziehung zueinander, scheint es doch als würde es sich um zwei Seiten einer Medaille handeln.

Eine eingeschränkte Selbstbestimmungsfähigkeit ist eine akzeptable Rechtfertigungsgrundlage für Paternalismus. Bejaht man, begründet durch eine mangelhafte Autonomiefähigkeit des Patienten, dass paternalistisches Intervenieren gerechtfertigt ist, und wird der Patient somit für einwilligungs*un*fähig erklärt, dann ist dieses Urteil wohl legitim. Es fragt sich aber, ob auch andere Begründungen genügen, die sich weniger klar auf ein Konzept von Selbstbestimmungsfähigkeit berufen.

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[30] Äußerliche Faktoren, die paternalistische Interventionen legitimieren, werden von anderen Voraussetzungen der informierten Einwilligung abgedeckt (mangelhafte Information, Manipulation durch Dritte).

Das obige Beispiel mit dem wahnbedingten Behandlungsverzicht zeigt, weshalb ein zu enger Fokus auf die Autonomiefähigkeit problematisch sein kann. Im Fall des psychotischen Patienten könnte der behandelnde Arzt wie folgt argumentieren:

> *Es handelt sich um einen Patienten mit einer psychiatrischen Erkrankung, die unter anderem durch phasenweise schwere Störungen des Realitätsbezugs in Form von Halluzinationen, Ich-Störungen und Wahn gekennzeichnet ist. Der in der konkreten Entscheidungssituation wirksam werdende Wahn stellt eine ausgeprägte Fehlbeurteilung der Realität dar. Wobei diese Fehlbeurteilung zu einer Einschätzung der Situation führt, die der Patient höchstwahrscheinlich ohne die akute Erkrankung so nicht teilen würde, und die in dieser Form jeglicher einfühlsamer Nachvollziehbarkeit entbehrt und somit als ausschlaggebender Grund für den Patientenentscheid in Anbetracht der Schwere der Konsequenzen des Entscheids—schwerwiegende, irreversible Schädigungen sind wahrscheinlich—nicht anerkannt werden sollte und es deshalb geboten ist—zum Schutz des Patienten—seinem Entscheid nicht Folge zu leisten.*

Reicht diese Argumentation aus, um ein Urteil von *Einwilligungsunfähigkeit* zu legitimieren?—Akzeptiert man nur Begründungen, die sich strikt auf ein Konzept von Selbstbestimmungsfähigkeit abstützen, ist es schwierig, die Güte dieser Darlegung abschließend zu beurteilen. Es ist nämlich nicht eindeutig, ob die vorgebrachten Argumente auf eine eingeschränkte Selbstbestimmungsfähigkeit hinweisen oder diese überhaupt betreffen. Für eine genauere Prüfung muss unter anderem geklärt werden, ob die Kriterien für Selbstbestimmung nur prozessualer Art sind oder auch inhaltliche, werthaltige Kriterien beinhalten, oder welches Verständnis von Authentizität ausschlaggebend ist, denn die vorgebrachten Argumente setzen exakt bei diesen Punkten an (vgl. Oshana, 2006; Owen et al., 2009; Salmela & Mayer, 2009). So ist das Argument einer ausgeprägten Fehlbeurteilung der Realität und der damit einhergehenden fehlenden Nachvollziehbarkeit der Gründe des Patienten nicht mit einem wertneutralen Verständnis vereinbar. Der Glaube an außerirdische Unionen wird in diesem Fall nicht mehr bloß als exzentrische Eigenart, sondern als eine pathologische Normabweichung aufgefasst. Ebenfalls spielt eine bestimmte Vorstellung von Authentizität eine Rolle insofern nicht das gesunde und damit authentische Selbst des Patienten, sondern die vorübergehende Erkrankung für den Entscheid verantwortlich gemacht wird. Beide Argumente stehen in einem engen Zusammenhang mit dem Vorliegen einer psychiatrischen Diagnose, die ihrerseits normativ konnotiert ist.

Die Argumente ließen sich eingängig auf ihre Probleme hin untersuchen. Das Authentizität-Argument erweist sich zum Beispiel in Fällen von chronifizierten psychischen Erkrankungen als problematisch, weil eine Gleichsetzung von *gesund* und *authentisch* respektive *krank* und *nicht-authentisch* nicht mehr in gleicher Weise funktioniert. Unter theoretischen Gesichtspunkten und hinsichtlich der Forderung nach generalisierbaren Standards könnte also durchaus gefolgert werden, dass die vorgebrachten Argumente nicht Bestandteil einer Definition von Selbstbestimmungsfähigkeit sind und sie damit eine Zuschreibung von *Einwilligungsunfähigkeit* nicht zu legitimieren vermögen. Dennoch bleibt die moralische Intuition, den psychotischen Patienten zu seinem Schutz zu bevormunden. Dies wiederum führt dazu, dass die Kriterien für Selbstbestimmung oder EF abermals in Frage gestellt werden; und erneut ist man mit der Schwierigkeit konfrontiert, wertneutrale und allgemeingültige Standards zu formulieren. Eine zu rigide Ausrichtung am Begriff der Selbstbestimmungsfähigkeit führt also immer wieder in Sackgassen und ist tendenziell wenig hilfreich.

Obwohl die dargelegte Begründung sich nicht auf eine klare Definition von Selbstbestimmung abstützt, beruht sie dennoch auf Argumenten, die ein solches Konzept tangieren und dabei ausreichend stichhaltig und nachvollziehbar erscheinen sowie auf breiten Konsens stoßen, dass sie eine Bevormundung und damit ein Urteil von *Einwilligungsunfähigkeit* zu legitimieren vermag. Auf alle Fälle handelt es sich nicht um Gründe, die sich auf persönliche, als alleingültig erachtete Werte und Ansichten der beurteilenden Person berufen und damit klarerweise ungerechtfertigt paternalistisch wären.

Eine solche Vorgehensweise negiert keineswegs die Bedeutung der Autonomiefähigkeit des Patienten für die Beurteilung von EF. Sie bietet vielmehr eine Möglichkeit, mit der Ambiguität dieses Begriffs besser umzugehen, indem sie sich nicht rigide an einem bestimmten Verständnis orientiert oder universell gültige Kriterien fordert—im Falle einer inhärenten Fähigkeit wäre dies Voraussetzung—, sondern Raum für alternative Vorstellungen von Selbstbestimmung schafft. Was für die Zuschreibung von EF zählt, ist nicht in erster Linie die Überprüfung vordefinierter Kriterien für mentale Fähigkeiten, sondern eine nachvollziehbare Begründung, weshalb in einem konkreten Fall fürsorglich eingegriffen werden soll. Dabei kommt man nicht umhin, Charakteristika des Patienten gründlich zu explorieren. Ausgangspunkt der Beurteilung von EF bilden moralische Intuitionen, deren zugrunde liegenden Faktoren spezifiziert und untersucht werden sowie auf ihren Stellenwert für die Beurteilung von EF geprüft werden. Anschließend folgt ein Abwägen der gewonnenen Informationen unter Einbezug moralischer Prinzipien und eine

argumentative Begründung für oder gegen ein Urteil von *Einwilligungsunfähigkeit*. Die fachliche Urteilsbildung mit ihrer moralischen Komponente rückt somit ins Zentrum, wobei EF als Resultat dieser Einschätzung dem Patienten von außen zugeschrieben wird.

Stellenwert der Folgen und der Nachvollziehbarkeit eines Entscheids

Divergente Vorstellungen von EF sind für bestimmte konzeptuelle und praktische Kontroversen verantwortlich. Die Beobachtung, dass EF insbesondere dann in Frage gestellt wird, wenn es sich um eine folgenreiche medizinische Entscheidung handelt, oder wenn sich der Patient gegen den Ratschlag des Arztes äußert, ist tatsächlich irritierend und nicht zu erklären, wird EF als eine inhärente Eigenschaft verstanden. Denn eine Eigenschaft der Person hängt nicht von äußeren Faktoren wie der Tragweite der Konsequenzen oder Divergenzen mit der beurteilenden Person ab. Wenn EF hingegen als Urteil verstanden wird, an dessen Grundlage Überlegungen bezüglich der Zulässigkeit von Paternalismus sind, ist die obige Beobachtung durchaus nachvollziehbar. Die Tendenz, paternalistisch einzugreifen, zeigt sich nur dann, wenn überhaupt die Möglichkeit einer Schädigung des Patienten besteht; sie nimmt mit der Schwere der Konsequenzen einer medizinischen Entscheidung gar zu. Gleiches gilt für Situationen, in denen der Patient eine aus medizinischer Perspektive suboptimale Behandlungsoption wählt, wenn seine Wahl für die beurteilende Person also nicht nachvollziehbar ist. Ist die beurteilende Person nun aufgefordert, ihre Tendenzen im Rahmen eines Urteils von *Einwilligungsunfähigkeit* zu rechtfertigen, und führt sie bloß an, dass paternalistisches Eingreifen deswegen geboten ist, weil der Patient einen Entscheid trifft, der aus medizinischer Perspektive nicht nachvollziehbar ist, dann mangelt es an einer akzeptablen Begründung. Eine Zuschreibung von *Einwilligungsunfähigkeit* ist in diesem Fall unzulässig bevormundend. Begründet die beurteilende Person ihre Tendenzen hingegen dahingehend, dass der Patient die relevanten Informationen nur unzulänglich verstanden und insbesondere deren Tragweite nicht vollständig erfasst hat und dass er deswegen zu diesem unverständlichen Entscheid gekommen ist, dann handelt es sich um eine angemessene Begründung, die den spezifischen Merkmalen des Patienten Rechnung trägt.

Die Konsequenzen und die Nachvollziehbarkeit eines Patientenentscheids spielen bei der Beurteilung von EF also insofern eine wichtige Rolle, als dass sie Zweifel respektive moralische Intuitionen bei der beurteilenden Person evozieren. Für sich alleine betrachtet, legitimieren sie jedoch keine Bevormundung (Buchanan & Brock, 1989).

Auch in Bezug auf die Frage, ob risiko-relative Beurteilungen angemessen sind, ergeben sich unterschiedliche Antworten, je nachdem welches Verständnis von EF zugrunde liegt (vgl. Brock, 1991; Wicclair, 1991b). Konzipiert man EF als inhärente Fähigkeit, die durch klar umschriebene Kriterien näher spezifiziert ist, bedeutet Risiko-Relativität ein variables Definieren dieser Kriterien in Abhängigkeit der Tragweite der medizinischen Entscheidung. Das heißt konkret, dass bei schwerwiegenden Konsequenzen höhere Anforderungen an die mentalen Fähigkeiten gestellt werden, also entweder bessere oder zusätzliche Fähigkeiten verlangt werden (Buchanan & Brock, 1989). Dies ist nicht mit dem Begriff einer inhärenten Fähigkeit vereinbar, denn eine solche definiert sich ja gerade nicht über äußere Faktoren. Zusätzlich impliziert eine risiko-relative Herangehensweise aufgrund der variablen Kritieren, dass es im Grunde nicht nur eine, sondern verschiedene Einwilligungsfähigkeiten gibt und dass man sich je nach äußeren Gegebenheiten auf die eine oder andere bezieht. Das ist nicht nur konzeptuell problematisch, sondern mutet tatsächlich willkürlich an und schürt den Verdacht, es handle sich bei einer solch flexiblen Handhabung der Kriterien um eine elegante Möglichkeit, unzulässigen Paternalismus über die Hintertür einzuführen (Wicclair, 1991b).

Denkt man EF hingegen als ein Urteil, das auf einem begründeten Votum für oder gegen eine Bevormundung beruht, ist die Berücksichtigung der Konsequenzen viel weniger problematisch. Mehr noch: Eine vollständige Begründung kommt nicht umhin, die Tragweite der medizinischen Entscheidung mitzureflektieren. Sie ist es, die den Fähigkeiten des Patienten gegenüber gestellt wird und bestimmt, ob diese unzureichend sind (vgl. Grisso & Appelbaum, 1998a). Dieser Sachverhalt wird gut im obigen Bespiel des psychotischen Patienten illustriert, wo ein fürsorgliches Eingreifen mit der verzerrten Realitätswahrnehmung und der schwerwiegenden, irreversiblen Schädigung des Patienten begründet wird, wobei diese Begründung kaum weiter argumentativ zu unterlegen und letztlich eine Ermessenssache ist (Grisso & Appelbaum, 1998a).

Die Berücksichtigung der Konsequenzen eines Entscheids mutet im Fall einer inhärenten Fähigkeit also willkürlich und konstruiert an, im Fall eines ethischen Urteils ist sie integraler, nicht wegzudenkender Bestandteil der Bestimmung der EF. Somit kann die Debatte um risiko-relative Beurteilungen größtenteils als Folge der hier beschriebenen konzeptuellen Unklarheiten verstanden werden.

Einwilligungsfähigkeit als ethisches Urteil: Einige Implikationen

Wir haben dargelegt, dass EF tatsächlich und sinnvollerweise als ethisches Urteil angegangen wird. Dennoch liegt das Schwergewicht in der Diskussion auf einzelnen Kriterien: Die valide, reliable und objektive Erfassung mentaler Fähigkeiten wird zur Ausgangslage für die Beurteilung von EF gemacht. Zu diesem Zweck werden standardisierte Instrumente bereitgestellt und somit gewissermaßen suggeriert, es handle sich um eine inhärente Fähigkeit (z.B. Grisso & Appelbaum, 1998b). Kann man allenfalls von der Idealvorstellung einer inhärenten Fähigkeit nur schwer Abschied nehmen? Und wieso bereitet es Mühe, die moralische Dimension von EF anzuerkennen? Es scheint fast so, als wäre man bestrebt, in Anbetracht der negativen Konnotation des Paternalismus-Begriffs das scheinbar Ungebührliche, das ihm anhaftet, vom Konzept der EF fernzuhalten. Sie deshalb als inhärente Fähigkeit zu konzipieren ist jedoch nur eine vermeintlich elegante Lösung. Wir plädieren dafür, die moralische Dimension von EF stärker anzuerkennen und sie zur Grundlage der Beurteilung von EF zu machen, anstatt die Messung von Fähigkeiten an erste Stelle zu setzen. Das bedeutet, die beurteilende Person stärker mit der Frage zu konfrontieren, ob sich ihre Tendenz, fürsorglich eingreifen zu wollen, legitimieren lässt, und sie daraufhin aufzufordern, gute Gründe zu nennen und Gegenargumente zu reflektieren.

Gleichfalls muss ein Umdenken hinsichtlich der Art und Weise stattfinden, wie Fachpersonen bei der Bestimmung von EF unterstützt werden. Stellt man ein Hilfsmittel bereit, so muss dieses derart aufgebaut sein, dass es der beurteilenden Person hilft, ihren Zweifeln und Intuitionen auf den Grund zu gehen. Dieses Instrument muss mögliche Gründe für eine Entscheidung strukturieren und so einen relativ offenen Rahmen bieten, um Zweifel systematisch zu explorieren. Faktoren, die es zu berücksichtigen gilt, sind einerseits Merkmale des Patienten, wie beispielsweise sein Informationsverständnis, seine Krankheits- und Behandlungseinsicht oder seine Entscheidungsmotive, andererseits aber auch entscheidungsspezifische Aspekte, wie die Tragweite der Konsequenzen, sowie Faktoren, die den beurteilenden Arzt und den weiteren gesellschaftlichen Kontext betreffen, insbesondere im Hinblick auf vorherrschende Werthaltungen. Die Gesamtheit dieser Faktoren kann Zweifel generieren und muss somit kritisch auf ihren normativen Gehalt und Stellenwert innerhalb der Beurteilung von EF untersucht werden, bevor sie unter Bezugnahme auf moralische Prinzipien abgewogen und in einem abschließenden Urteil integriert werden. Ein solches Hilfsinstrument ist nicht auf eine beschränkte Anzahl Kriterien festgelegt, sondern öffnet das Feld für alternative Positionen, die ein weiteres,

durchaus begründetes Verständnis von Selbstbestimmung vertreten. Dies schließt all diejenigen Aspekte mit ein, die gegenwärtig als relevant für EF erachtet und diskutiert werden, die jedoch (noch) keinen Eingang in den traditionellen Kriterienkatalog gefunden haben, wie beispielsweise Werte oder Emotionen (z.B. Banner, 2012; Cox White, 1994). Weitere Implikationen ergeben sich auch für die Qualitätssicherung des fachlichen Urteils. Das Augenmerk liegt dabei nicht bloß auf der Beurteilung der Fähigkeiten des Patienten, indem sichergestellt wird, dass diese valide und reliabel erfasst werden; ebenso gründlich sollte die abschließende argumentative Begründung bezüglich ihrer Qualität untersucht werden.

EF als ethisches Urteil zu denken, bedeutet, in eine Dialektik zu treten zwischen dem Grundsatz der *informierten Einwilligung* und ihrer rechtlichen Verankerung—Paternalismus ist legitim, weil der Patient einwilligungs*un*fähig ist—und dessen Umkehrung, nämlich dass der Patient einwilligungs*un*fähig ist, weil sich Paternalismus legitimieren lässt. Die beurteilende Person legt dar, weshalb eine Bevormundung legitim ist, und stellt EF—verstanden als inhärente Fähigkeit—nicht lediglich fest. Anstatt also die zentrale Frage nach der angemessenen Grenze zwischen zulässiger und unzulässiger Bevormundung an das Konzept der EF als Selbstbestimmungsfähigkeit zu delegieren, rückt diese Grenzziehung stärker in den Fokus und wird zur eigentlichen Aufgabe. Es geht darum zu bestimmen, in welchem Maß die Merkmale des Patienten, der Entscheidungssituation sowie Faktoren seitens der beurteilenden Person und der Gesellschaft—oft finden diese implizit Eingang in die Beurteilung[31]—eine fürsorgliche Fremdbestimmung legitimieren. Dies hat den Vorteil, dass eine nuanciertere Betrachtung möglich wird und auch kritischer Reflexion und Diskussion mehr Platz eingeräumt werden kann. Die Frage, ob es sich um zulässigen oder unzulässigen Paternalismus handelt, muss nicht mithilfe bestimmter Definitionen und einzelner Kriterien beantwortet werden, sondern kann sich stärker an der Spezifität und Komplexität einzelner Fälle ausrichten.

Durch die Betonung der fachlichen Urteilsfindung wird auch die Rolle der beurteilenden Person und die daraus abgeleiteten Verantwortlichkeiten und Pflichten im Rahmen der Bestimmung von EF stärker thematisiert. Es ist naheliegend, dass die Aushandlung dieser Rolle in der Beziehung zum Patienten die Urteilsfindung beeinflusst und dass das Ergebnis bis zu einem gewissen Grad spezifisch für ein bestimmtes Rollenverständnis ist. Insofern ist die Autonomie des Patienten in ihrer Ausübung nicht nur eine Funktion der inneren Merkmale des Patienten, sondern relational, durch die wahrgenommenen Rollen und

[31] See publication 4.

Verantwortlichkeiten der involvierten Personen mit bestimmt (vgl. Mackenzie & Stoljar, 2000).

Die Anforderungen an die beurteilende Person werden mit einem solchen Verständnis von EF gleichfalls anspruchsvoller. Profunde Kompetenzen in ethischer Entscheidungsfindung und ein Wissen über damit einhergehende relevante Aspekte, Fragen und Schwierigkeiten sind Voraussetzungen. Des Weiteren verlangt ein solches Vorgehen ein höheres Maß an Einsichtsfähigkeit, Bereitschaft zur Selbstkritik, Artikuliertheit und nicht zuletzt auch Zeit. Es bleibt zu klären, inwieweit solche Forderungen die ärztlichen Kompetenzen überschreiten, der Ärzteschaft in ihrer klinischen Arbeit überhaupt zumutbar sind oder eine Überforderung bedeuten.

Fazit

Ausgangspunkt der vorliegenden Arbeit waren Unklarheiten hinsichtlich des Grundverständnisses von EF. Dabei wurde insbesondere der Frage nachgegangen, ob EF eher ein inhärentes Merkmal des Patienten oder ein ethisches Urteil bezeichnet. Für diese Unklarheit sind widersprüchliche Tatsachen und Annahmen verantwortlich respektive Diskrepanzen zwischen Idealvorstellungen, der möglichen und tatsächlichen Herangehensweise. Einerseits verweist der Begriff der Einwilligungs*fähigkeit* auf eine mentale Fähigkeit des Patienten. Es geht vorwiegend um die Definition angemessener Kriterien für EF und deren valide und reliable Erfassung. Patientenmerkmale stehen also im Vordergrund und man bemüht sich, das Konzept in einem weiteren Rahmen mit dem Begriff der Autonomie- oder Selbstbestimmungsfähigkeit zusammenzuführen. Andererseits ist EF eine Voraussetzung für die *informierte Einwilligung* und damit nicht losgelöst von moralischen Prinzipien denkbar. Sie beruht letztlich auf einem umfassenden fachlichen Urteil und basiert ihrerseits bereits auf einem Abwägen des Patientenschutzes einerseits und des Respekts vor dem Entscheid des Patienten andererseits. Mit dieser Gegenüberstellung wird gleichsam klarer, woher die Schwierigkeiten mit dem Konzept herrühren. In dem Moment, in dem EF als Voraussetzung für die *informierte Einwilligung* Geltung erhält, besteht sie nicht mehr als unabhängige, implikationslose Größe, sondern entscheidet darüber mit, ob dem Patienten die volle Entscheidungshoheit zukommt und er ein Recht auf Selbstbestimmung hat. Aufgrund der Ambiguität des Begriffs der Selbstbestimmung und insbesondere kraft moralischer Intuitionen beginnen ethische Überlegungen in die Definition und Bestimmung von EF einzufließen. Die Frage *Ist der Patient einwilligungsfähig?* wandelt sich zur Frage *Soll der Patient für einwilligungsfähig erklärt*

werden?, womit EF keine inhärente Fähigkeit, sondern nur das Resultat eines ethischen Urteils meinen kann (vgl. Banner, 2012; Brock, 1991). Bei der Beurteilung von EF geht es folglich um eine Zuschreibung von Entscheidungshoheit und somit um die Frage, ob eine Bevormundung unter Berücksichtigung der inneren Merkmale des Patienten und der äußeren Umstände moralisch richtig oder falsch ist. Bloß anzunehmen, es gehe um die Bestimmung der Fähigkeit des Patienten, eine selbstbestimmte Entscheidung zu treffen, greift zu kurz, weil diese Annahme der moralischen Dimension von EF nicht angemessen Rechnung trägt.

Denkt man EF zudem als ethisches Urteil, klären sich weitere Unklarheiten, so zum Beispiel die Frage nach dem Stellenwert der Konsequenzen oder der Nachvollziehbarkeit des Patientenentscheids. Außerdem eröffnen sich neue Wege, die Beurteilung von EF anzugehen, unterstützende Hilfsmittel zu gestalten und Fachpersonen angemessen zu schulen.

7.2 Beyond the Traditional Criteria: Personal Values and Emotions in the Evaluation of Medical Decision-Making Capacity

Helena Hermann, Manuel Trachsel, Bernice Elger, and Nikola Biller-Andorno (submitted). Beyond the traditional criteria: Personal values and emotions in the evaluation of medical decision-making capacity. *Medicine, Health Care and Philosophy.*

Abstract

Ever since the traditional criteria for medical decision-making capacity (*understanding, appreciation, reasoning, evidencing a choice*) were formulated, they have been criticized for not taking sufficient account of emotions or values that seem, according to the critics and in line with clinical experiences, essential to competence. The aim of this paper is to provide a narrative review of the contributions emphasizing the importance of these factors and arguing for their inclusion in competence evaluations, and to discuss these findings from a meta-perspective. The arguments for including emotion and value in decision-making capacity assessment prove to be diverse. Moreover, a nuanced and case-sensitive understanding of their impact on competence is required.

Introduction

Patients' decision-making capacity or competence is the gatekeeping element establishing the role of patient choices.[32] In view of the legal and ethical implications, the concept has been intensely investigated both theoretically and empirically over several decades.

One long-standing debate concerns the definition of relevant criteria of competence, in terms of mental abilities or of patient characteristics more generally. In the 1990s, great advances were made by Thomas Grisso and Paul S. Appelbaum, who distilled and systemized relevant mental abilities on the basis of United States case law (Appelbaum & Grisso, 1995). These extensive works yielded the four traditional criteria that have remained influential ever since: (1) *understanding* refers to the ability to comprehend treatment-related information, such as information about the present disorder, treatment options, and related risks and benefits; (2) *appreciation* refers to the ability to acknowledge that one is suffering from a particular disorder (i.e., insight into the disorder). It also refers to the ability to recognize the consequences for oneself of the disorder and of potential treatment options, including the ability to acknowledge that treatment could be beneficial (i.e., insight into the necessity of treatment); (3) *reasoning* refers to the ability to manipulate information rationally, using logic to compare the risks and benefits of treatment alternatives; and (4) *evidencing a choice* refers to the ability to communicate a choice (Grisso & Appelbaum, 1998a).

While these standards have some validity and have significantly helped to improve competence evaluations, they have been and continue to be challenged. Critics characterize the traditional approach as too cognitive and/or too procedural in failing to take proper account of non-cognitive factors and/or substantive elements (Banner, 2013; Charland, 1998b). Specifically, critics advocate for fuller acknowledgment of emotional factors and values within competence evaluations.

Various and sometimes overlapping or even conflicting arguments have been advanced in favor of this claim. However, an overview of the relevant literature fails to provide a comprehensive understanding of the significance of emotions and values in competence evaluation, making any significant advance in this matter difficult. To overcome this barrier, this paper conducts a narrative review of the medical ethics literature with regard to existing arguments for stronger recognition of emotions and values in competence evaluations, and

[32] Although there is a distinction made in parts of the literature concerning the terms decision-making capacity and competence, we use the terms interchangeably in this paper.

discusses the findings from a meta-perspective.[33] To our knowledge, no such review has to date been undertaken. With this review and the discussion of the findings, we hope to reactivate the debate and to stimulate further development.

The relevant arguments are clustered into four groups, from the most developed category to the least: (1) *procedural understandings* of the impact of *emotions*; (2) *procedural understandings* of the impact of *values*; (3) *substantive understandings* of the impact of *emotions*; and (4) *substantive understandings* of the impact of *values*. In discussing the findings, the specific difficulties of formulating and measuring emotional and valuational factors are highlighted. The intention is to invite reflection on the possibility of handling relevant factors in a more flexible, case-specific, and context-specific way rather than adhering to a predefined and rigid set of criteria. The findings of the review are summarized in Table 2.

Emotion and Value

It is not a coincidence that emotions and values are discussed together, as they share a common feature: their evaluative function (Charland, 2006; Kluge, 2005). Both a person's emotions and their personal values provide information about the specific valence of aspects of the world—emotions in more affective terms and values by means of more elaborated, reflective endorsement. Although emotions and values covary and overlap, it seems useful to review the literature in terms of these two categories, as in most cases either the affective dimension or the individual's set of reflectively endorsed values is emphasized. The terms *emotion* and *value* are used here in a relatively broad sense, in line with their wide range of usage in the literature, from affective arousal to gut feelings and from more abstract values to more concrete preferences.

Epistemic beliefs, which also play an important role in competence, are further to be distinguished from emotions and values. Such beliefs pertain to a person's (mis)perception of reality or their responsiveness to evidence, as captured under the traditional *appreciation* standard. Delusion in the course of a psychotic episode is the paradigm case in which a patient's competence is questioned due to distorted beliefs (Grisso & Appelbaum, 1998a). There is a conceptual difference between making a decision based on untrue beliefs about reality and being responsive to evidence but basing a decision on an evaluative judgment relating to those facts. Differentiating between beliefs and evaluative elements such as emotions and values is therefore important for conceptual clarity.

[33] Further debates in philosophy with regard to autonomy and its relation to emotions and values are not included in this review.

Procedural and Substantive Accounts

The distinction between procedural and substantive understandings of the impact of values and emotions on competence is of fundamental importance. This relates to discussions of whether or not competence, and more generally the concept of personal autonomy, is content-neutral (value-neutral) or content-laden (value-laden) (Freyenhagen, 2009; Owen et al., 2009).

The prevailing procedural account is characterized by its sole focus on *formal* requirements as the only reflective processes used in arriving at a decision, or on the structural character of the underlying values, preferences, and desires (Mackenzie & Stoljar, 2000). As long as these procedural demands are met, people are allowed to make decisions on whatever grounds they choose—rational or irrational. Procedural accounts are motivated by the principle of respecting pluralism in society and therefore refrain from judging the lifestyle, value system, viewpoint, or reasons underpinning a decision as more or less appropriate.

Against this, substantive accounts claim that to resist consideration of a patient's motives is a failure to take adequate account of real conditions and so renders competence evaluations less meaningful (Freyenhagen & O'Shea, 2013). Here, the *content* of reasons underpinning a decision is scrutinized and judged as either problematic or unproblematic for competence. Insofar as personal values and emotions serve as reasons, they are potentially subject to such substantive judgments, which are always value-laden in prescribing what kinds of emotions or personal values are acceptable. Clearly, then, substantive requirements restrict pluralism to some extent (Freyenhagen & O'Shea, 2013).

Table 2. Arguments for acknowledging emotion and value in decision-making capacity.

	Emotion	**Value**
Procedural understanding (content-neutral)	Emotions provide crucial information and are essential in decision making - Full "appreciation" requires emotion - Strong emotional avoidance/denial is problematic Affective arousal derails cognitive functions and overpowers rational thought "Too little" or "too much" of emotional engagement is problematic Habitual patterns of emotional processing matters - Recognition of intraindividual norms is important Emotions impede authentic decision-making - Emotions impact on the coherence of preferences - Affectively first-order desires conflict with second-order desires	Values provide a "conception of the good" and are essential in decision making Minimally stable and consistent values are required for (authentic) decision making *Pathological values* deriving from a mental disorder impede authentic decision making
Substantive understanding (content-laden)	Emotions decrease responsiveness to evidence - *Concretized emotion-belief complex* - Preoccupation with or denial of risks and benefits Problematic emotions - Feelings of indifference concerning one's own welfare - Pathological hopelessness Affectively driven under- or overvaluation of risks and benefits	Rationality of values matters Weighing and balancing information (*reasoning*) means to assign the right value to each item of information Values that denigrate the status of the decision-maker as a person are problematic

Importance of Emotions from a Procedural Perspective

The literature deals most extensively with the impact of emotions from a procedural or content-neutral perspective. Arguments concern the necessary and appropriate extent of emotional involvement, the negative impact of emotions on cognitive faculties, the role of habitual patterns of emotional processing, and the undermining of authenticity by emotion.

When Patients Remain Unemotional

Advocacy for the inclusion of emotions in competence evaluations derives to a great extent from observation, and from the acknowledgement that emotions have an essential function in decision making that adds incrementally to contributions from cognitive or analytical capacities.[34] In support of this argument, repeated reference is made to neuroscience and to the paradigm case of patients with lesions in the ventromedial prefrontal cortex, as described at length by Antonio Damasio (Appelbaum, 1998; Charland, 1998b). Despite their fully restored intellectual capacities, these patients make disastrous decisions in complex everyday situations by virtue of their 'hard-wired' inability to incorporate affective cues into their decision-making process (Damasio, 1994). Accordingly, the positive functions of emotions in decision-making are emphasized by those who advocate stronger recognition of emotional factors in competence evaluations. Emotions are seen to constitute a specific source of knowledge that provides us with crucial information about the overall nature of our current situation, including internal states as well as external events. They tell us about the personal value and meaning of aspects of our world and are therefore essential in generating, defining, and keeping track of our goals and preferences. Furthermore, emotions motivate us and lend reason to our choices. In sum, they help to promote our well-being and enable us to reach value-congruent or authentic decisions.[35] In light of these positive effects of emotion, it is argued that an overriding ignorance or suppression of affective cues—or a substantially impaired capacity for emotion—makes it impossible to incorporate essential information into the decision-making process. Decisions are then made without complete information, and this is considered an impediment to competent decision making (Charland, 1998a; 1998b; Cox White, 1994; Silverman, 1997).[36] A substantial absence of emotion is seen to constitute a loss, potentially leading to choices that are grossly detached from a person's self

[34] See publication 3.

[35] See also publication 3.

[36] See also publication 3.

and anchored solely in objective facts.[37]

More specifically, it is argued that emotional engagement and processing is crucial to a full appreciation of one's situation (Charland, 1998a). The argument is advanced that a merely intellectual grasp of being personally affected by a particular clinical condition and by the consequences of disease or of potential treatment options (the traditional understanding of *appreciation*) is insufficient. Alternatively, appreciation is conceived as understanding, in a more experiential sense, what the consequences would really entail—for example, „what it would be like and 'feel' like to be in possible future states and to undergo potential alternatives." (Buchanan & Brock, 1989, p. 24). Indeed, it is both disturbing and dubious when a patient remains totally dispassionate and without emotion when confronted with a life-threatening disease or a serious medical decision.[38] Mental states characterized by strong emotional avoidance, significantly impoverishing the ability to appreciate the personal relevance of information, are relevant in this regard (Rudnick, 2002). Therefore, Silverman (1997, p. 171-172) argues that, for competence, „individuals must be able to pay attention to emotions, recognize them as relevant information, remember their relationship to past and preferred states of affairs, and determine whether acting on such emotions will further their well being."

When Patients are Overwhelmed by Emotions

Imagine a patient who experiences intense affective arousal in the aftermath of a serious diagnosis or due to another labile condition, so that she appears overwhelmed by intense emotions, perhaps, cannot stop crying, to the extent that feelings totally overpower rational thought. Basic mental functions such as concentration, attention, or the ability to retain information are impeded to the extent that she does not meet minimal requirements for understanding and deliberation (Banner, 2012; Cox White, 1994). Such cases are grounds for paying attention to emotional factors because they negatively impact on cognitive abilities, or on the traditional criteria.

Both the preceding and present argument touch on the question of the appropriate level of emotional involvement or on the inclusion of affective cues in patients' decision-making (Banner, 2012; Brown, 2011). In some cases, as for example in the lesion patients mentioned above, competence is challenged because too little attention is paid to emotional information;

[37] See also publication 3.

[38] See also publication 3.

in other instances, affective arousal is so disproportionate as to overpower cognitive faculties. Kluge (2005) differentiates between the *appropriateness* of emotions (referring to their *quality* or *content*), which can be more or less adequate under particular circumstances, and the *strength* of an emotion, which, by contrast, is concerned with the *quantity* or *degree* of emotional involvement. From a procedural perspective, only the latter seems of interest, in that it is about the extent of emotional engagement and not about the quality or content of the emotion *per se*.

When Patients Process Emotions in an Unusual Way

Imagine a patient who has been consulting a physician for years, so that her personality and preferences are well known to the physician, who is acquainted with her intuitive and emotionally-driven decision-making style. On a particular occasion, however, she is unable to attend to or rely on her emotions, and behaves in a calculating and distanced way that clearly deviates from her usual conduct (Cox White, 1994). In these circumstances, concerns may arise about the patient's competence; the same would apply to a patient who is known to be quintessentially rational but suddenly relies only on their gut feelings. Such cases are seen to call competence into question because the person decides in a manner that is unusual from an intra-individual perspective. Abrupt changes in patients' conduct generally warrant caution, as they indicate that something is disordered (Grisso & Appelbaum, 1998a). Moreover, Becky Cox White (1994, p. 137) argues that „Letting a patient make decisions without the evaluations he normally considers important and worthy of attention permits him to go astray from the structuring or restructuring of his life plans"; this in turn is regarded as an impediment to the patient's well-being and autonomy of choice.

On the flip side, as long as a person complies with her usual decision-making style, there is no reason to question her competence even if she decides in an overly emotional or overly rational manner. Cox White (1994), for example, holds that it is not legitimate to deem a person incompetent only because they are generally unemotional and quintessentially rational, never expressing their emotions because they do not allow themselves to experience them; to overrule a person's typical response fails to respect his individuality.

In similar vein, Mackenzie and Watts (2011b; 2011a) discuss the implications of an emotional capacity standard for the so-called neurodiverse, such as a person diagnosed with an autism spectrum disorder, who might by such a standard be at risk of being unjustifiably deemed incompetent by virtue of their abnormal emotionality. In their view, respect for this unemotional decision-making style is warranted because it is usual for that person.

In sum, appropriate attention must be paid to person's decision-making style.[39] However as the literature suggests, considerations of style and preferences might conflict in certain instances with the required minimum degree of emotional involvement as outlined above.

When Patients Decide Inauthentically on the Basis of Affective States

Another cluster of reasons for considering emotional factors as relevant to competence touches on the notions of authenticity and accountability as criteria for competence (Elliott, 1991). As Brown (2011, p. 199) observes, striking mood shifts or labile conditions seem to „undermine a person's decision making from within as if there were no one executive decision-maker whose authority is recognized by competing mental states, as if a federation were functioning without any central government." When a person is affected by deep depressive feelings, for instance, their values, desires, beliefs, and dispositions are often so dramatically changed that their decisions are widely inconsistent with their authentic character in a healthy state. The patient's choices are not truly theirs but more a result of their mental illness, and they seem not fully accountable for their decisions (Elliott, 1997). Similarly, Rudnick (2002, p. 153) argues that „pervasive emotional states or moods impact on preferences by regulating their relative weights and perhaps less commonly by generating new preferences, thus modifying the set—and hence the coherence—of preferences held by the individuals experiencing these moods." While regarding such incoherence as problematic for competence, Rudnick (2002) also acknowledges the challenges posed by chronic depression or dysthymia, where changed preferences are so persistent and ingrained in personal identity that one can hardly describe them as inauthentic.

Authenticity or accountability may also be threatened in instances where, according to Harry Frankfurt (1971), affectively driven first-order desires conflict with a person's second-order desires. This is often observed in persons suffering from addiction and may also apply to persons with certain phobias (Charland, 2002; Frankfurt, 1971). Imagine, for example, a person who is fully aware of the benefits of treatment and is keen to have it (second-order desire) but is so terribly afraid of hypodermic needles that they take flight in panic on encountering same (first-order desire).

[39] See also publication 3.

Importance of Personal Values from a Procedural Perspective

In line with the prevailing procedural account, the second most elaborated cluster of arguments claims to recognize personal values in a content-neutral manner, encompassing such fundamental concerns as the indispensability of a stable set of values for decision-making in general and for competence in particular, together with more sophisticated reasons related to authenticity.

When Patients Lack an Elaborated Value System

Imagine a patient suffering from advanced dementia who is increasingly losing his sense of self, including his conception of what is valuable to him and what he considers desirable to strive for. Although he can momentarily indicate his needs by showing pleasure or aversion, he is no longer able to align these responses to a represented set of personal values, making it impossible to evaluate any information about an upcoming treatment or to reflect on the factors underlying and motivating a choice. Alternatively, one may think of a 13 year-old girl who meets all the cognitive standards but is only beginning to develop a sense of her adult self and her own conception of the desirable. Again, her values may not yet be sufficiently elaborated to properly balance relevant treatment information. In both cases, competence is challenged on the grounds that a personal value system and a related capacity to assign personal significance to one's options are essential in decision-making. This is particularly true if competent decisions are to result in choices that are personally meaningful, based on reflections about one's motives, and potentially beneficial for the decision-maker's subjective well-being (Buchanan & Brock, 1989). People need a 'conception of the good' against which they can weigh and evaluate alternative treatment options (Buchanan & Brock, 1989). In other words, concepts of value provide reference points for reflection, explanation, and justification of one's motivation for choosing a particular alternative. If a patient does not possess a sufficiently elaborated set of values in which their decisions are embedded, no meaningful or autonomous choices can be made, and competence is called into question (Breden & Vollmann, 2004; Buchanan & Brock, 1989; Kluge, 2005).

When Patients Lack Consistent Values

The mere presence of values, however, seems insufficient. For competence, it is additionally required that these values are minimally stable and consistent over time (Charland, 2001; Craigie, 2013; Kluge, 2005). It is argued that „sufficient value stability is needed to permit, at

the very least, a decision that can be stated and adhered to over the course of its discussion, initiation and implementation" (Buchanan & Brock, 1989, p. 25)—otherwise, one can hardly develop consistent plans, and risks being caught in motivational conflicts (Kluge, 2005). Imagine a cancer patient who must decide whether he wants to continue with curative treatment that might prolong his life or to stop it and begin with palliative care. He is torn between the options and constantly changes his mind, struggling with whether to give priority to extension of life or a peaceful death and caught in a strong ambivalence that he cannot overcome by himself.

Consistency of values is closely related to the notion of authenticity, in that decisions made on the basis of enduring personal values will also appear authentic (Mackenzie & Watts, 2011b). However, it is problematic to take an enduring set of values as a criterion for either authentic or competent decision-making, given that values evolve and change over time, or may even undergo radical change in particular situations—as, for example, in drastic end-of-life circumstances (Craigie, 2013; Mackenzie & Watts, 2011b).

When Patients Rely on Inauthentic Values

A heated debate has arisen concerning the relation between values and authenticity in the context of mental disorders—more specifically, with reference to anorexia nervosa (Charland, 2006; Grisso & Appelbaum, 2006; Tan et al., 2006; Tan, Stewart, & Hope, 2009; Vollmann, 2006; Whiting, 2009). Tan and colleagues (2006) coined the term *pathological values* to circumscribe those values of anorexic patients that originate from their disorder rather than from the individual themselves. They argue that decisions based upon such *pathological values* challenge competence because these values are not authentic or in line with that person's expected values if they were not affected by a mental disorder. In the anorexic patient, for example, overvaluation of thinness may be regarded as pathological insofar as it is a causal consequence of anorexia nervosa—a mental disorder characterized by, among other things, the diagnostic criterion of intrusive fear of fatness—and so belongs to the disease rather than to the individual (Tan et al., 2006). Moreover, this overvaluation of thinness is likely to vanish when the disorder abates, and vice versa (Charland, 2006). It appears then that justifications of incompetence based on *pathological* or *inauthentic* values are closely bound to or apply only in the context of a diagnosed mental disorder (Tan et al., 2009). Furthermore, as previously discussed in the context of affective disorders and authenticity, challenges may arise when anorexic patients experience an enduring change of personal identity, where the disorder becomes so constitutive of self that patients can no

longer imagine being free of it (Hope, Tan, Stewart, & McMillan, 2013; Tan et al., 2006). Intriguingly, Hope and colleagues (2011) have shown that many patients suffering from anorexia nervosa experience the disorder as separate from the real self, distinguishing between an *authentic real* self and an *inauthentic anorexic* self. However, others experience their anorexia „not as a separate self but as integral to a single self." (Hope et al., 2011, p. 24), calling into question whether we can still speak of inauthentic values in these cases.

Importance of Emotions from a Substantive Perspective

A third cluster of arguments concerns the substantive or content-laden influence of emotions on competence. Interestingly, most of these contributions do not pertain directly to the content of emotions but argue for their indirect impact on substantive elements by way of epistemic beliefs. Insofar as such beliefs rely upon epistemic norms that are content-laden, the manner of their constraint by emotion is best discussed from a substantive perspective. By contrast, there are no explicit and profound analyses or justifications of the appropriateness of specific emotive reasons in the context of competence. There are only some theoretical reflections, especially in relation to depression, that more or less implicitly allude to the relevance of emotions from a substantive point of view.

When Patients Misperceive Reality Due to Affective States

Emotions are also seen to impact negatively on competence by affecting the patient's responsiveness to evidence, their perception of reality, or their epistemic beliefs, respectively. In terms of the traditional approach, one might say that affective factors impact negatively on the *appreciation* criterion.

An elaborated account on the impact of emotion on epistemic beliefs is presented by Jodi Halpern (2011; 2012), who labels the competence-impoverishing interplay she describes as a *concretized emotion-belief complex*. At the core of her argument lies the observation that there are patients who are caught in an affective state—often in the aftermath of a traumatizing or shocking event—that is frequently accompanied by catastrophic thinking, rendering them unable to feel differently in the present or to imagine feeling differently in the future. In addition, they are unable to grasp that they are subject to this emotional point of view and that their current affective state directly impacts on their epistemic beliefs about the future. As a consequence, their cognitive responsiveness to evidence is undermined, as is their ability to deliberate meaningfully on the future (Halpern, 2012).

Similarly, Meynen (2011) argues that in depression a person's perception of the world and of their possibilities certainly changes, even to the point of substantial bias that would be considered problematic for competent decision making. As Bursztajn and colleagues (Bursztajn et al., 1991, p. 386) note, affective disorders are often characterized by „an emotionally involving, self-convincing preoccupation with the risks of treatment coupled with denial of the benefits." It is the profound feeling of hopelessness that can render the depressed patient incapable of envisioning any possibility of recovery or even of relief from suffering (Leeman, 1999).

Comparable effects have been observed and discussed in the context of anorexia nervosa, whose characteristic signs include strong anxiety associated with eating to put on weight and related negative feelings such as self-disgust on seeing one's body. These feelings lead anorexic patients to a judgment that they are too fat, which is counterevident from an objective point of view. Although often able to see and intellectually grasp the objective evidence, their affective responses prompt these patients to believe differently and to assess their weight against a purely subjective standard (Hope et al., 2013). In short, they lack affective responsiveness to objective norms and evidence.

When Patients Rely on Problematic Emotions

Proponents of a substantive account of competence place particular emphasis on the reasons underlying a patient's choice, and on the judgment of these reasons as more or less appropriate or supposedly 'recognizable' (Banner, 2012; 2013; Charland, 1998b; Freedman, 1981). It is further acknowledged that emotions constitute a particular class of reasons and are therefore subject to such evaluation.

Depression is an affective disorder characterized by hopelessness, helplessness, deeply entrenched feelings of guilt and worthlessness, anhedonia, and other symptoms. These feelings are likely to affect the value assigned by patients to themselves, to their lives, and more specifically to the treatment options and outcomes they face. One likely consequence of such feelings is that a patient will become largely insensitive to their own welfare, perhaps to the point of not caring about risk, or even positively valuing negative consequences such as death (Elliott, 1997; Freyenhagen & O'Shea, 2013). That being so, should we ever consider someone's deep feelings of worthlessness as a legitimate or 'recognizable' reason to refuse life-saving treatment? Bursztajn and colleagues (1991, p. 384) argue that „affective disorders may impair competence in a detectable and identifiable way, primarily influencing the meaning and weight given to treatment risks and benefits." And Rudnick (2002) points to felt

indifference and the problem of undervaluing positive outcomes in depression—both of which, he says, undermine competence. Other authors only touch on these substantive features; Sullivan and Youngner (1994), for example, point to the difficulty of distinguishing between realistic and pathological hopelessness among terminally ill patients.

By the same token, most of these authors are also aware of the challenge inherent in substantive approaches in terms of the value judgment they entail: „Assessing a patient as emotionally incompetent may bring us once again into the difficult realm of distinguishing the competency assessor's values or preferences for treatment from the patient's emotional state." (Glass, 1997, p. 22). Halpern (2011; 2012) takes an explicit position that declines to deem a depressive patient incompetent if they undervalue life. According to her, as long as the depressed person retains their cognitive abilities and is responsive to evidence, his or her values and choices should be respected.

Importance of Personal Values from a Substantive Perspective

In the realm of values, analyses of their relation to epistemic beliefs (as in the context of emotions) do not exist, or values and beliefs are wrongfully equated (Grisso & Appelbaum, 2006). Moreover, the predominant argument in the literature concerns why the content of values matters, but in-depth analyses of specific types of values remain rare.

When Patients Rely on Problematic Values

From a substantive perspective, personal values are considered relevant to competence in that they provide reasons on which to base decisions. As such, they are subject to normative judgments regarding their appropriateness. Charland (2001, p. 139), for example, states that „simply having values is not enough. A certain kind of rationality is also required." He stresses that normative considerations associated with value can never be eliminated from the evaluation of competence. Imagine, for instance, a man suffering from a disease requiring hospitalization and treatment for at least two weeks. He refuses treatment, explaining that he does not want to stay away from home for so long, leaving his precious plants behind. He accepts the potential health impairments as long as he can stay with his many plants—his dearest companions. In such a case, discussion may proceed from whether or not his reason to forego treatment is sufficiently 'recognizable' or rather indicative of incompetence.

Other authors are more specific, arguing that judging a person's capacity to use, weigh, and balance information—termed *reasoning* in the traditional approach, where it is regarded as a

purely procedural standard—necessarily involves a normative judgment (Banner, 2012; 2013; Holroyd, 2012). In saying that a person is properly weighing and balancing information, we refer not only to the logical consistency of their argumentation but also to whether the person assigns to each item of information its due significance for the decision-making process, or weighs the information appropriately. Accordingly, Holroyd (2012, p. 157) provocatively asks whether „weighing information requires that certain specific commitments and rankings are held?" In the context of anorexia nervosa, one could then say, for instance, that the patient is „improperly valuing nourishment and giving too much weight to food avoidance and maintaining a low weight." (Holroyd, 2012, p. 157) From this perspective, we would then speak of *pathological values* because these are inherently problematic rather than merely impeding authentic decisions (Vollmann, 2006).

A more concrete stance on why particular values are problematic is taken by Kluge (2005). He suggests that values that „denigrate the status of the decision-maker or others *as person*" (p. 299)—and therefore inherently conflict with principle-based values that acknowledge the equal and intrinsic moral worth and dignity of human beings, as proclaimed in the Universal Declaration of Human Rights—challenge competent decision-making. As an example, he cites the octogenarian who foregoes life-saving treatment because she perceives herself to cause a burden as an unproductive member of society and of her family.

Proponents of a substantive understanding of competence are entirely aware of the well-known risks of arbitrariness and undue paternalism in making value judgments (Breden & Vollmann, 2004; Radoilska, 2012; Tan et al., 2006; Whiting, 2009) and try to find ways of dealing with the implied challenges (Banner, 2013; Banner and Szmukler, 2013; Freedman, 1981; Freyenhagen & O'Shea, 2013). It goes beyond the scope of this paper to provide a full review of existing proposals for dealing with these problems or identifying a solution. However, in line with Freyenhagen and O'Shea (2013), we believe that increased transparency or explicit discussion of the values and beliefs guiding competence evaluations, as well as democratic contestability of conditions for competence and intersubjective validation of judgment, can help to reduce the risk of arbitrariness.

Discussion

In this paper, the literature on the role of emotions and personal values in medical decision-making competence has been reviewed. Without offering a detailed normative justification for the inclusion of emotions or values in competence evaluations, the review provides a

summary and overview of arguments and justifications advanced elsewhere. To that end, these arguments are assessed within four categories, from most to least elaborated, bringing conceptual clarity and identifying research gaps. In this way, it contributes to ongoing discussion and provides a starting point for delving more systematically into specific concerns, placing a stronger emphasis on clinical correlates.

The following discussion presents a meta-perspective on these findings to sensitize readers to the specific challenges arising in this area.

Overlapping Themes

The literature on the subject proves to be quite extensive, and provides a variety of reasons for including emotion or value in competence evaluations. Furthermore, a closer look at these arguments reveals the complex nature of competence. Although we have tried to sort the literature within a structuring framework in the interests of more conceptual clarity, things might not be as clear-cut in reality, given the overlap between emotion and value and the interplay between cognition and emotion, and where a distinction between procedural and substantive factors is not always easily established.

This review shows that similar themes emerge in the realms of emotion and value. Both are relevant as indispensable elements in decision making—or, indeed, as a potential threat to the authenticity or accountability of a decision. Furthermore, consistency over time plays a role, in terms of a habitual pattern or style of emotional engagement on the one side and a minimally stable set of values on the other side. Moreover, both emotion and value figure as reasons underpinning a decision that can be more or less appropriate in certain circumstances. As already mentioned, there is also a conceptual overlap; emotions seem to include a valuational component, and rationally endorsed values are likely to be accompanied by some emotional involvement. As a consequence, we may attribute competence-undermining aspects to either domain, of emotion or value. In the context of anorexia nervosa, for example, the prevailing discourse speaks of *pathological values* (Tan et al., 2006), but a few prefer to talk about *pathogenic affective states* (Charland, 2013). In respect of other disorders, such as depression, the opposite seems to hold, as a majority argue from the point of view of emotions.

Different Possibilities for Interpretation

In general, it seems that different phenomena can be interpreted from different angles. To illustrate this, let us revisit the patient who is so afraid of hypodermic needles that he

refuses treatment against his better knowledge and intent. This case was discussed in relation to Frankfurtian second- and first-order desires, and so was conceived as an issue of authenticity or accountability (Frankfurt, 1971). However, one could equally argue otherwise, by demonstrating that this anxiety is so strong that it totally overwhelms rational thought, or cognitive abilities—or otherwise again, by judging it from a substantive perspective and arguing that the anxiety is so irrational that we cannot accept it as an appropriate reason to forgo treatment.

All of these arguments appear somehow plausible, so that questions arise, first, about which of these arguments provides the right justification for an incompetence judgment, and second, which of them reflects our actual reason for doubting the patient's competence. It seems unlikely that univocal answers to these questions can be obtained but rather that all of these aspects together, reflecting the specificity and complexity of the case, cause us to question competence and help us to justify an incompetence judgment.

Case-Specificity

The specificity and complexity of cases therefore seem important, and this is supported by other observations from the literature. Issues of value stability, emotional involvement and authenticity-impoverishing impacts of emotions and values all require more or less subtle differentiation to be indicative for incompetence. A certain degree of value stability is necessary, but people should also be allowed to change values radically; emotional involvement that is too weak or too strong appears indicative of incompetence, but this depends on the extent to which cognitive abilities are affected, or on the person's usual decision-making style—even, perhaps, on the causes for inappropriate emotional engagement. An inability to incorporate affective cues may be differently interpreted in the context of precisely discernible brain damage than in the context of a neurodiverse condition such as autism. Furthermore, the authenticity or accountability argument seems to work particularly well in the context of a diagnosed mental disorder that implies a distinction between a diseased inauthentic and a healthy authentic self. There again, however, no universal claims apply, as it seems necessary to differentiate between the acutely and chronically diseased. Finally, the substantive account of emotions and values appears particularly case-sensitive, even to the point of being accused of total arbitrariness.

The absence of precise criteria concerning emotion and value in competence evaluations is unsurprising, as such criteria could be formulated only conditionally and with an undefined number of 'if' provisions. It appears, then, that emotions and values cannot be

judged in isolation but only in light of their interaction with each other and with other factors. In place of predefined, rigid criteria, a more elastic approach is clearly required.

Reconciliation Efforts

The difficulty to formulate criteria in terms of emotions or values seems to contrast with the current traditional approach, which purports to give well-defined, universally applicable, clearly operationalized and objectively verifiable criteria. In this light, efforts to take into account more ambiguous and complex soft factors such as emotion and value appear to represent a great threat for proponents of the traditional approach, who usually defend their view and argue against emotional or valuational criteria by presenting various arguments.

In the first place, they may refer to the authority of the US law from which the traditional criteria are derived, arguing that modifications of the legal doctrine require rigorous proof of the need for other criteria, as well as further consideration of the costs involved in changing the legal practice (Appelbaum, 1998; Grisso & Appelbaum, 2006).

On the other hand, they may argue that the traditional criteria in fact capture those patients who are presumably lacking emotional or valuational capacity (Grisso & Appelbaum, 2006), and that some non-cognitive factors are already implicit in the traditional account (Kim, 2010). For instance, in the debate on *pathological values* in anorexia nervosa, Grisso and Appelbaum argue that the traditional *appreciation* criterion already includes some consideration of values (Grisso & Appelbaum, 2006). To establish this link, they equate values with epistemic beliefs: „In fact, the analysis of most cases of lack of appreciation find values, applied in a manner that involves a distortion of reality, at the heart of the matter" (Grisso & Appelbaum, 2006, p. 295). They then illustrate the range of distorted beliefs underpinning the decisions of anorexic patients—for example, their belief that they are fat, although in reality they are just skin and bones. Certainly, these beliefs challenge competence, but they provide a justification that differs from judging the value of thinness as problematic for competence because it can hardly reflect an authentic value in the context of anorexia nervosa. It seems, then, that Grisso and Appelbaum merged the notions of value and belief to bring discussion of *pathological values* back within the confines of the traditional approach.

A similar mechanism can be observed with regard to the notion of 'appreciation', one of the four traditional standards clearly defined and operationalized by Grisso and Appelbaum but also occurring in ordinary language, with quite ambiguous and versatile meanings.

Authors may speak of an appreciation of consequences and mean quite different things; for some, it means being responsive to evidence, while for others it refers to the ability to emotionally grasp the personal significance of the consequences, and for still others it implies an allocation of proper weights to each consequence. Thus, ostensibly operating within the confines of the traditional approach, it is actually about value and emotion.

Operationalizing and Measuring Emotions

Opponents of an emotion-inclusive approach to DMC further argue that emotions need to be clearly operationalized and measurable in a reliable manner before being included in DMC evaluations (Appelbaum, 1998). This is indeed a challenging or even conclusive argument, as it seems more difficult as well as inappropriate to provide technical operationalizations and measurements for emotions comparable to those used in the assessment of cognitive faculties. Emotional processing seems not only more subjective but also to require more contextually embedded evaluation that is sensitive to the person in their entirety. Moreover, relational aspects such as empathy seem to play a crucial role in the perception and evaluation of emotional components—it is rather about understanding patients than measuring them. In this light, a rethinking of assessment procedures to take proper account of emotional factors seems worthwhile.

Dealing with Different Requirements

To conclude, there seems to be a tension between the desire to retain some legally binding criteria—universally applicable, value-neutral, concise, and slight as possible—that can serve as points of reference, especially in the case of legal proceedings, and the requirement to take proper account of the complexity and specificity of single cases—the nuanced occurrences, interplays, and differentiations of mental processes, and their embedding in normative frames which together touch on our intuitions to challenge a person's competence.

It is open to discussion how to reconcile these two requirements and to balance the advantages and disadvantages of a minimalistic and a more comprehensive and case-specific approach. Nevertheless, it appears that we currently tend to interpret the existing standards too narrowly, even try to adhere desperately to them (as the above-mentioned reconciliation efforts show), and sometimes forget that there is actually a scope of discretion giving latitude to the peculiarities of individual cases. After all, the traditional criteria were inferred from case law, perhaps too directly translated into standardized

measures, so that in the course of this translation the case-based approach was inappropriately replaced by a standardized frame into which each case subsequently had to fit.

Directions for Future Research

We understand the literature on emotion and values to be an attempt to explore the scope of discretion and peculiarities applying to single or groups of cases, and to provide a nuanced and case-sensitive understanding of the factors that cause us to question a person's competence. The formulation of additional criteria seems not to be—and, in light of the aforementioned difficulties, cannot be—the primary purpose of these contributions. Nonetheless, these analyses are crucial, as they help to sensitize those who must evaluate and justify incompetence to the multifold and case-related interplays between contextual factors, various mental faculties, and their normative underpinnings. In general, a stronger focus on case analysis seems promising for arriving at a still more nuanced understanding of competence (Owen et al., 2009).

In particular, investigations of substantive accounts, both regarding emotions and values, seem worthwhile as they are relatively underrepresented in current analysis. This would include further elaboration of how to conceive and deal with related problems of unjustified paternalism and arbitrariness.

As seen at different points in the review, the presence of a diagnosis of a (mental) disorder and the normative presumptions underpinning such categorizations seem to affect our understanding of how emotions and values impact on competence. Further investigations of these interactions may be also useful in sharpening our awareness of the complex interplays in competence evaluations.

7.3 Accounting for Intuition in Medical Decision-Making Capacity: Rethinking the Current *Reasoning* Standard?

Helena Hermann, Manuel Trachsel, and Nikola Biller-Andorno (accepted). Accounting for intuition in medical decision-making capacity: Rethinking the current *reasoning* standard? *Philosophy, Psychiatry, & Psychology.*

Abstract

Given the ethical implications of assessments of decision-making capacity, adequate definitions and appropriate assessment criteria are essential, especially with regard to clinical practice in psychiatry. Currently applied standards have been criticized for emphasizing exclusively cognitive abilities. In particular, the present paper questions the adequacy of the current *reasoning* criterion. Referring to dual-process models of decision-making, it is argued that the *reasoning* standard embraces only one side of the duality that is rational deliberation, and fails to take proper account of intuitive decision-making. An outline of intuition's potency in healthcare decisions informs the present account of why the current *reasoning* standard fails to take adequate account of patients' decision-making preferences and of major deficits in intuitive reasoning. Towards a more comprehensive understanding, a possible reconceptualization of reasoning as the ability to decision-related *self-reflection* is advanced, and implications for evaluation, challenges, and limitations are discussed.

Introduction

A patient's decision-making capacity or competence (DMC) is among the prerequisites for valid consent to medical treatment, and is regarded as the gatekeeping element in ensuring respect for patients' self-determination. The issue is especially relevant in the case of vulnerable persons, such as patients who are cognitively or mentally impaired, and where medical decisions carry far-reaching consequences (Grisso & Appelbaum, 1998a).

As a grounding principle, DMC is a priori assumed, and challenged only when substantial doubts arise due to observed or assumed deficiencies of the capacities commonly considered relevant for competent decision-making (Berghmans, 2001); in this sense, the onus is on proving incompetence rather than competence.

Among the capacities of relevance here is the patient's ability to integrate relevant information, which essentially involves connecting and relating single items of information and weighing and balancing them. In the DMC literature, this capacity is explicated under the so-called *reasoning* standard and defined by Appelbaum and Grisso (1995) as the ability to manipulate information rationally, using logic to compare the risks and benefits of treatment alternatives. To achieve a perfect score on the *reasoning* standard in the MacCAT-T—the most sophisticated available assessment tool for evaluation of DMC—the patient is required a) to mention at least two specific treatment-related consequences when explaining their choice (e.g., „With medication, the voices I hear will go away"); b) to make at least one statement in the form of a comparison of at least two options (e.g., „With treatment X, I am more likely to be able to walk than with treatment Y"); and c) to identify at least two reasonable everyday consequences (e.g., „With medication Y, it sounds like I might be drowsy a lot—could be dangerous at work"). In addition, the final choice must derive logically from the analytical reasoning inherent in the patient's responses when explaining the choice (Grisso & Appelbaum, 1998b).

This definition of *reasoning* has prevailed since its development in the mid-1990s, and it still guides evaluations of patients' DMC today. However, because of their wider relevance, information integration and decision-making have been under continuous scientific scrutiny over recent decades. This has led to psychological theories and empirical insights favoring a model that distinguishes two systems or modes of information processing or decision-making—a deliberative and an intuitive mode (Evans, 2010). These so-called dual-system theories assign particular features to each processing mode or system.

System 2, the deliberative mode, is characterized by processing that is conscious, analytical, reason-based, verbal, and relatively slow, with limited information processing capacity. By

contrast, System 1, the intuitive mode, is distinguished by faster, automatic, unconscious, and holistic processing, with high information processing capacity. Moreover, System 1 processing is often associated with emotions, and usually manifests in a gut feeling or intuition that is by definition not entirely susceptible to rational explanation. In such cases, a decision just 'feels' right, and one finds it difficult to account fully for either the decision or the underlying feeling (T. Betsch, 2008b).

It has further been suggested that these two modes or systems operate in parallel and influence each other (Epstein, 2008). In general, neither system is seen to be superior to the other; each has its strengths and limitations, and the best decisions may well draw upon the complementary effects of both (de Vries, Fagerlin, Witteman, & Scherer, 2013).

Returning then to the concept of DMC, in trying to assign the *reasoning* standard to one of these two decision-making modes, it soon becomes clear (in how it is conceptualized and operationalized) that *reasoning* strongly resembles the rational deliberation or analytical processing of System 2. In particular, it is commonly assumed that DMC entails an immediate ability to reconstruct and verbalize our own decision-making processes in quite mechanistic and calculating fashion, and more emotion-driven and implicit processes are not currently taken into account.

Based on the substantial body of research in empirical sciences, there seems then to be a discrepancy between our knowledge of human decision-making and our understanding of the mental abilities required for competence as defined by the *reasoning* standard. The aim of the present paper is to scrutinize this gap and to advocate more explicit and stronger recognition of intuitive processing in DMC. Despite acknowledgement that intuition can contribute meaningfully to competent medical decisions (e.g., Breden & Vollmann, 2004),[40] this proposition has rarely been interrogated in more detail. To this end, the following outline of the role of intuition in decision-making, and its unique contribution to competent medical choices, precedes an elaboration of why and how DMC evaluations must respect patients' individual decision-making styles and preferences while also taking proper account of major deficits in intuitive and analytical processing. In this light, shortcomings of the current *reasoning* standard are discussed, and conceptual refinements of this standard are proposed toward achieving a more integrative understanding. In addition, some practical suggestions are offered on how to live up to these propositions during the patient encounter.

[40] See also publication 5.

The Merits of Intuition in Patients' Medical Decision-Making

Arguments for stronger recognition of intuition in the evaluation of DMC are strengthened not only by the evidence that intuitive processing is an integral part of decision-making but by demonstrating how intuition can contribute meaningfully and incrementally to competent medical decisions.

In the context of judgment and decision-making, intuition has long been equated with heuristic processing, mental shortcuts, and biases (e.g., Gilovich, Griffin, & Kahneman, 2002); but critical voices have claimed that intuition lies beyond these phenomena. Some scholars have proposed an alternative view of intuition that strongly incorporates a learning perspective. Sadler-Smith (2008) for example defines intuition as

> *an involuntary, difficult-to-articulate, affect-laden recognition or judgment, based upon prior learning and experiences, which is arrived at rapidly, through holistic associations and without deliberative or conscious rational thought* (p. 31).

The following outline of the role of intuition in patients' medical decision-making considers instances where intuition unfolds its full power by capitalizing on the richness of prior experience. The emphasis here is not on heuristic processing and biases, but rather on how intuitive processing is found to be holistic, efficient, and eventually highly accurate.

De Vries and colleagues (2013) present an overview of some general strengths and pitfalls of both intuitive and deliberative decision-making in a healthcare context. They credit intuition with two powerful advantages which, it will be argued, contribute essentially to competent medical decisions.

The first of these advantages is that intuition allows patients to integrate a large amount of information simultaneously, resulting in a compelling feeling that may accurately reflect the patient's best choice, by virtue of its comprehensiveness. By the same token, this is a drawback of deliberation or analytical processing, which is by contrast limited in its information processing capacity, leading the patient to focus on perhaps a few salient treatment features, which may be easier to articulate but not necessarily decisive (Wilson & Schooler, 1991). This strength of intuitive processing is particularly relevant for healthcare decisions, as they are often of high complexity, must be made under pressure of time, and require the patient to process various kinds of information—not only about treatment options and their associated risks and benefits, but also about long-term consequences for the patient's life or social environment. Confronted by such a large and multi-faceted amount of information, a reasoning mode that is able to process information simultaneously and almost without capacity restrictions would seem both useful and

efficient. Moreover, intuitive processing can be seen to contribute to the comprehensive understanding of relevant information, prerequisite for competent decision-making.

A second advantage of intuition by comparison with rational deliberation is its greater sensitivity to feelings and affective cues in the process of preference construction. This is clearly of importance in light of growing evidence that emotions are pertinent sources of information, as highlighted for example in neuroscientific research that has led to the somatic marker hypothesis proposed by Damasio (1994). This hypothesis suggests that aspects of a current situation may trigger the reactivation of bodily states—partly expressed as experienced feelings—based on previously learned contingencies between situation-specific factual knowledge and somatic markers. In the DMC literature, the present argument finds support from Becky Cox White (1994), who details the relevance of affect in competence evaluations, showing that emotional responses can signal the experienced significance of a particular situation or event.

In many cases, medical decisions are of great personal significance, as the patient's health or even life may be at stake. There is often no single best choice of treatment, and trade-offs are inevitable; in such situations, the patient's preferences and values come into play in determining what is best for them. Such preference-sensitive decisions clearly require the patient to be able to know and explicate those preferences and values, and it can be quite challenging both to elucidate the values patients assign to the benefits and harms of treatment alternatives, and to help them to communicate their views to others involved in the decision-making process (Stacey et al., 2014). One way of achieving this is by supporting the patient to combine beliefs about their options with basic values they may hold (Feldman-Stewart et al., 2012). The central question then is how patients know or come to know about their own basic values, which are normally considered as self-attributed motives, consciously and verbally represented and therefore available to self-report (McClelland, Koestner, & Weinberg, 1989). Though they are potentially measurable through self-report, abstract value concepts such as autonomy, affiliation, hedonism are at the higher end of the goal hierarchy; as such, it may be unduly optimistic to assume that every person can readily retrieve such values, or identify them as part of his or her concept of self, while making or explaining a personal choice. Because these self-attributed values are not always readily accessible, more bottom-up affective cues may be crucial indicators that something highly appreciated is at stake (Aarts & Custers, 2012).

Beyond this presumed difficulty in accessing and verbalizing one's self-attributed values in timely fashion when making a decision, there is evidence that not all the motives guiding

human action are conscious and verbally encoded. In motivation research, it is widely acknowledged that the distinction between implicit and explicit or self-attributed motives is of fundamental importance. By comparison with explicit motives or values, implicit motives are not lingually acquired, and therefore are not consciously represented (Weinberger & McClelland, 1990). Instead, implicit motives are understood as motivational dispositions deriving from basic human needs, directed to attaining specific classes of incentives, and avoiding specific classes of disincentives. Moreover, such motives are tightly linked with strong affective responses to motive-specific triggers, and to accompanying situational cues (Schultheiss, 2008). These findings suggest that consideration of affective factors in decision-making becomes highly relevant when implicit motives are involved.

It would seem then that intuition's sensitivity to affective cues may be of particular relevance in medical decision-making, given that such decisions are likely to affect a patient's basic needs and values, and therefore to trigger affective responses. Such affects may have an adaptive function, informing the patient as to his or her values and motives, and whether they are currently being achieved (Cox White, 1994). Taking such affects into account may help to achieve value-congruent judgments, and can therefore contribute meaningfully to competent medical decisions (Breden & Vollmann, 2004; Buchanan & Brock, 1989).

Interindividual Differences in Decision-Making Preferences and Styles

While decision-making is usually a blend of intuitive and analytical processing, it is known that individuals display more use of one or other mode, depending on features of the situation, as well as on individual preferences for a certain decision-making style (C. Betsch, 2008a).

From knowledge of ourselves or others, we all know that we are either more inclined to pore over a decision—perhaps listing pros and cons of alternatives and their respective weights—and to think it through thoroughly (analytical decision maker), or that we may prefer to let the decision sink in while doing something else, trusting our gut feelings as they evolve and crystallize (intuitive decision maker).

People tend to favor either intuition or deliberation and may tend to adopt their preferred strategy even where the situation invites stronger recognition of the other reasoning mode

(C. Betsch, 2004). In short, individuals differ in their reliance on either implicit or explicit knowledge (C. Betsch, 2008a), and in their use of feelings or of cognitions as a criterion for decision-making (Schunk & Betsch, 2006). Moreover, it has been demonstrated that persons who make decisions in accordance with their reasoning preferences tend to evaluate outcomes more positively and experience less regret about their decisions (C. Betsch & Kunz, 2008).

Together, these observations confirm the need to adequately account for a patient's decision-making style and preferences, both generally in treatment decisions and, more specifically, in the evaluation of DMC. This claim is supported by Grisso and Appelbaum (1998a):

> *Some people choose impulsively, preferring to avoid prolonged deliberation. Others 'go with their gut', relying on emotional or intuitive factors to guide them in their decisions. It is their right to make choices as they please, so long as mental disorders or limitations on cognition do not prevent them from doing otherwise.* (p. 54)

On that basis, however, intuitive decision-making is not accepted unconditionally; major deficits in the ability to integrate information present a challenge for DMC.

Substantial Doubts about Patients' Ability to Integrate Information

Granted, then, that both intuitive and deliberative modes of reasoning have particular strengths and pitfalls that may support or hamper competent decision-making (de Vries et al., 2013), it seems evident that these systems are complementary and, indeed, mutually supporting. It is argued that any substantial impairment—on either the intuitive or the analytical side—may therefore provide grounds for questioning a person's competence. Indeed, any such impairment, on either side, must raise considerable doubts about a patient's DMC.

Imagine, for instance, someone who is no longer able to incorporate affective cues into his or her decision-making, as described by Damasio (1994). Such cases are characterized by lesions in the ventromedial prefrontal cortex (VMPC), an area of the brain responsible for integrating affective information in the decision-making process. Despite fully restored intellectual capacities, these patients are found to make disastrous decisions in real life by virtue of their deficient intuitive reasoning. They are no longer able to use affective cues, nor can they process information conveyed by the emotions, which may be pertinent in collating the abundant data presented by real life situations.

Beyond these specific cases, we are generally doubtful about a patient's DMC—especially in relation to high-stakes decisions—when they seem totally disconnected from their emotional self or remain absolutely dispassionate in discussing their life, as if they were uninvolved spectators. In extreme cases, they may calculate their best option solely by weighing advantages and disadvantages and their respective probabilities, in line with how physicians determine what is in their best interests. The decision is then based primarily on factual information and remains impersonal, as the patient is neither emotionally involved nor appreciative of subjective factors in making the decision. In these cases, it appears legitimate to question a patient's DMC on the basis of assumed major deficits in intuitive reasoning, and to initiate further examination accordingly.

In an alternate scenario, substantial doubts may also arise when patients appear completely immersed in their gut feelings and steered by their emotions without being able to minimally reflect on them or their decision. Again referring to Grisso and Appelbaum (1998a), these are presumably cases in which limitations on cognition prevent a patient from doing otherwise, where it seems legitimate to doubt and to examine DMC in light of suspected major deficits in analytical reasoning.

An examination of patients' intuitive or analytical reasoning is therefore required wherever there is substantial doubt regarding these capacities. It is argued that any such assessment must remain sensitive to patients' decision-making style and preferences, posing a challenge to the evaluator, who must account for an intuitive decision maker's gut feeling approach while assessing analytical capacities, and must equally explore the analytical decision maker's intuitive reasoning while respecting his preferences for rational deliberation. It is argued that this requires an elastic approach toward both the concept and assessment of reasoning, and this is considered a shortcoming of the current *reasoning* standard.

Is There a Need to Rethink The Current *Reasoning* Standard?

As outlined earlier, the definition and operationalization of the *reasoning* standard is strongly skewed toward a strongly analytical reasoning style, without due regard to intuitive elements, characterizing the competent decision-maker as calculating and purely rational. In its current form, it represents a clear-cut standard for classical rational deliberation or analytical reasoning. It is argued that this one-sidedness is problematic in two ways: first, it is unable to cope with suspected deficits in intuitive reasoning, and

second, it is not suitable to account adequately for the intuitive person's decision-making style.

With regard to the first claim, the current standard offers no means of confirming any doubts about suspected deficits in intuitive reasoning (e.g., VMPC lesion patients)—at least not by means of the *reasoning* standard, as these patients clearly comply with that criterion.

To substantiate this claim it would be necessary to establish whether any other existing criteria for DMC can capture intuition-based responses. In particular, the appreciation standard deserves further consideration; appreciation refers to the ability to appreciate the nature of one's disorder and the possibility that treatment could be beneficial. However, a closer look at this definition by Grisso and Appelbaum (1998a) reveals that it is concerned more with substantive aspects relating to content, such as *patently false beliefs* (Saks, 1991), rather than to information processing or integration. Others conceive appreciation differently, stressing the experiential sense of „what it would be like and "feel" like to be in possible future states and to undergo various experiences—and to integrate this appreciation into one's decision making" (Buchanan & Brock, 1989, p. 24). This conception comes very close to the notion of intuitive processing, but despite these similarities, it seems preferable not to subsume intuitive reasoning under the term appreciation, which is already ambiguous and variously defined. Instead, it seems useful to discuss intuitive reasoning discretely, in its relation to analytical reasoning as captured by the *reasoning* standard, allowing for a more nuanced understanding of relevant capacities and a finer distinction between substantive and procedural aspects.

Concerning the second claim, it is argued that analytical reasoning as conceived in the *reasoning* standard and assessed by the MacCAT-T is suboptimal in accounting for the intuitive decision-making style, so disadvantaging the intuitive decision maker. Imagine, for example, a person with a strong preference for intuitive decision-making or who is more comfortable with that decision-making style. It seems absurd to ask this person to write down a list of pros, cons, and weightings for different options in order to prove their analytical reasoning capacity; simply put, this is not how such a person makes decisions, and being urged to do so for verification of their analytical skills will not reflect their authentic decision-making. Instead, this may alienate and displease the patient, even evoking feelings of not being taken seriously. For these reasons, a different probing of reasoning seems indicated.

It is argued here that the MacCAT-T is inadequate for this purpose as it requires the patient to choose among the available options in a mechanistic way that clearly neglects the

intuitive decision maker's preferences. Granted, the MacCAT-T is a semi-structured interview and is therefore to some extent a flexible means of questioning and probing the patient, allowing their intuitions to be elicited and further explored. However, the instrument's mechanistic character is still apparent in the strict rating criteria, which are likely to influence how the patient is questioned. Using the MacCAT-T, the evaluator must rate four domains: *consequential reasoning, comparative reasoning, generating consequences,* and *logical consistency* (Grisso & Appelbaum, 1998b). For each domain, a rating of 0, 1, or 2 must be given, each concisely defined and operationalized, making the rating itself highly structured and analytical. It seems likely that such an analytical approach rubs off on patient requirements, as if the structured approach itself goes against a more holistic, intuition-based account. Clearly, then, evaluators using the MacCAT-T must be highly skilled in order to take proper account of a patient's intuitive reasoning and preferences while at same time adhering to the rating and probing instructions. Additionally, some degree of abstraction from the original operationalization also seems necessary. It follows that if some practitioners are less skilful in administering these DMC tools there is a risk that intuitive decision-makers will be disadvantaged by the analytical slant of both the *reasoning* criterion itself and of the test procedure. On the other hand, where evaluators are competent to take account of the needs of the intuitive decision maker—presumably by administering the MacCAT-T more elastically and by accepting deviations from the intended assessment procedure and scoring—it would make sense to directly rethink the assessment and the underpinning definition of the *reasoning* standard. So, what might a reconceptualization of *reasoning* look like if it were to capture substantial deficits in both analytical and intuitive processing while at the same time accommodating the individual's decision-making style?

How to Rethink Reasoning

As outlined above, patients' information integration or reasoning is called into question either by a lack of minimally required reflective abilities or because the patient's reasoning lacks any sense of personal involvement. An understanding of reasoning is therefore needed that will both allow for assessment of intuitive decision-makers' reflective capacities without requiring them to exhibit hardcore analytical reasoning and of analytical decision-makers' capacity to become personally involved and to connect with their emotions without forcing them to display full-fledged intuitive reasoning. On that basis, a reasoning standard is required that will not lock into one or other reasoning mode but is

instead more integrative. To this end, it seems worthwhile to take a step back and to ask what we wish to ensure by testing a patient's reasoning.

In so doing, we return to the conception of DMC as a patient's capacity for self-determination or autonomy in the context of healthcare decisions. While contemporary philosophical accounts of personal autonomy are varied, they share the idea that „autonomy, or self-determination, involves, at the very least, the capacity for reflection on one's motivational structure and the capacity to change it in response to reflection" (Mackenzie & Stoljar, 2000, p. 13). According to these authors, „Disagreements among different accounts of autonomy arise in explicating what is involved in the process of reflection, in explaining how reflection secures autonomy, and in making sense of the notion of "one's own"." (p. 13). Despite these varying specifications, most accounts of autonomy embrace both the notion of self (in terms of one's preferences, wants, needs, and values) and the general idea of reflection—and, in particular, critical self-reflection. Autonomous decisions are reached by reflective endorsement of one's reasons or motives for making a choice (e.g., Friedman, 2003). Finally, „By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are" (Dworkin, 1988, p. 20).

It appears that exactly these two components of self-reflection—self-reference and reflection—have fallen apart where there is substantial doubt about a person's reasoning, whether analytical or intuitive. Pure intuition is tied to the person's motivational structure but lacks the reflective component; pure analytical reasoning confirms a patient's thinking skills but substantially lacks self-reference, including connection to one's emotional self. To deem either type of patient competent, a practitioner must ascertain the interaction of those two components, constituting the integrative element of reasoning.

Conceived in this way, reasoning is then understood as the ability of the patient to engage in and arrive at a choice by means of self-reflection in light of the specific decision at hand, so bringing personal meaning to the situation, or making the decision one's own, respectively. This broader definition of reasoning can account for major deficits in intuitive reasoning and is better able to accommodate individual differences in decision-making styles.

Consider, for example, an 89-year-old woman with a mild cognitive impairment. Confronted with a difficult medical decision involving trade-offs between life expectancy and quality of life, the patient is emotional and can say quite quickly which option she prefers. She insists that the decision is really what she wants but has initial difficulty in

explaining her choice. In so doing, she apparently reveals herself as an intuitive decision-maker. However, doubts may remain, as it is unclear whether her conduct may be an expression of her deficient analytical reasoning. An examination of her reflective skills is therefore indicated. However, instead of requiring her to assess the available options in a mechanistic way that will fail to correspond to her decision-making preference, the physician could instead elicit the patient's intuitions and support her in further exploring them. If the patient responds to this support and is able to participate actively in a reflective process to concretize her intuitions, giving meaning to gut feelings in light of her explicit self-knowledge and the specific situation, then her self-reflective skills may be sufficient to deem her competent, given that the other required criteria for DMC—understanding, appreciation, evidencing a choice—are considered adequate. Presumably, her reasoning skills would hardly have been called into question if she had spontaneously initiated such a reflective process after communicating her choice.

It seems clear that this probing differs fundamentally from the mechanistic weighing and comparing of treatment options and their consequences, as is required by the traditional *reasoning* standard. Instead, intuitions provide a starting point and remain in focus during the reflective reasoning process.

Reasoning conceived as decision-related self-reflection also assists in probing the analytical decision-maker who is suspected to have major deficits in intuitive reasoning.

Imagine a young male rationalist patient who analyzes every treatment alternative and operates solely at the level of factual information about risks, benefits, and their respective probabilities while remaining totally impersonal and emotionally uninvolved. It seems difficult and pointless to demand that he should put his rational arguments aside to listen deeply inside himself and trace his gut feelings, in the interests of assessing his intuitive reasoning. Again, such an approach does not correspond to his preferred analytical decision-making style, but it is important to ascertain his ability for intuitive reasoning or self-referencing. In this case, it may also prove fruitful to depart from whatever he first offers to further explore whether he can relate these facts to personal information—his values, preferences, character traits, and experiential self-knowledge, as well as his fears and hopes. In addition, it would be important to see—in line with this focus on intuition—whether he is to any degree able to connect with his emotions, or to emotionally resonate while talking about himself. Beyond their psychic dimension, emotions find expression in statements, gestures, facial expressions, and modulations of the voice as received by others, helping an evaluator to identify the patient's emotional involvement.

It will be clear that this process differs from the intuitive decision maker's gut feelings approach in that it is less automatic, slower, and presumably less holistic; it is also likely to require more effort. Nonetheless, it is argued that this is sufficient to demonstrate a patient's ability for self-reflection with regard to a specific decision.

Both of these examples suggest that it seems worthwhile to redefine the *reasoning* standard as a patient's capacity for self-reflection—including reference to one's emotional self—in reaching a decision. As well as aligning with the common element in different philosophical accounts of personal autonomy, such a definition integrates the distinct intuitive and analytical tendencies of the mind. It also offers enough flexibility to respond adequately to the patient's pecularities in decision-making. Both intuitions and rational arguments—along with the patient's capacity for reflective endorsment or reference to self and motivational structure—are foregrounded, and the component that seems underrepresented can be further explored.

Fostering Reasoning through Dialogue and Narrative Involvement

The present suggestions for rethinking reasoning in DMC entail some general implications for the evaluation. First, in respect of the patient's exhibited reasoning mode, it seems essential that the evaluator should begin by getting a more detailed sense of the patient's decision-making preferences. What kind of decision maker is the patient? Is he or she more analytical or more intuitive? What does the patient offer when asked to explain his or her choice?

Second, the collected information should be taken as a starting point for further inquiries, determining how the evaluator proceeds and what kinds of questions he or she asks. Importantly, these questions and the manner of asking them should accommodate the patient's reasoning style. It seems inappropriate to go through a predefined set of questions designed to elicit answers that can be judged against preformed scoring criteria. The purpose of these questions is to set up a dialogue, and to stimulate further self-reflection on either the patient's intuitions or their rational arguments.

As these vignettes illustrate, especially in those cases evoking doubts, patients may experience intitial difficulty in accessing their subordinate reasoning mode, requiring substantial help to initiate and advance self-reflection. And it is in precisely this difficulty that we can see the great potential of a dialogical approach and of the narrative involvement of the patient as a means of both evaluating and substantially supporting and nurturing a patient's DMC.

Storytelling has come to be regarded as crucial in facilitating the creation of personal meaning and self-understanding, and therefore essential for the construction of personal identity (e.g., Angus & McLeod, 2004). As Bruner (2002) has suggested, narratives open up a space for self-reflection and self-construction by requiring people to interpret and make sense of their experiences. Furthermore, narratives are distinguished by their emotional import and the coherence that follows from the process of emplotment and the connection of different items of information (Goldie, 2012). As Angus and Greenberg (2011, p. 22) observed, „Our personal stories are given significance and salience when they become fused with emotion, and our emotions are given meaning when placed in their narrative context." In short, becoming involved in storytelling seems to bring together emotion and thinking, or the essentials of both, in intuitive and analytical reasoning, fostering self-reflection and ultimately self-understanding.

In the context of the physician-patient interaction, narrative can be conceptualized as the process through which patient and physician engage co-constructively in constant dialog in order to emphasize, interpret, and understand important information, events, and experiences (Angus & Hardtke, 1994). Angus and Hardtke (1994) further identify three distinct modes of inquiry when collaboratively engaging in narrative processing:

> *(a) the description of imagined or actual events; (b) the description of subjective experiences and feelings associated with those events; and (c) the reflexive analyses of feelings and events which have happened in the past, are occuring in the present or are anticipated for the future [...]* (p. 192)

Involving patients in narrative processes affords an opportunity for the physician to explore and probe patients' intuitive and analytical reasoning or their self-reflective skills, respectively. Moreover, it allows the co-constructively involved physician to provide adequate support to the patient, so enhancing their DMC and facilitating autonomous medical decision-making.

This in turn requires strong interpersonal and communication skills on the part of the evaluator, including the requisite competencies to establish a trustful and empathic atmosphere, in which the patient feels comfortable enough to tell his or her story. This might be considered a necessary or even crucial precondition for the full unfolding of a patient's potential and, by implication, valid assessment of his or her DMC.

Limitations and Challenges

In this paper, we have advocated stronger recognition of intuitive decision-making in DMC evaluations and suggested a rethinking of the current *reasoning* standard. The substantial body of empirical and theoretical insights into human decision-making, informing our outline of intuition's unique contribution to competent choices, substantiates these claims. Nevertheless, the ultimate decision to include intuitive reasoning as a criterion for DMC remains a normative matter.

One delicate concern in this regard has been raised by Appelbaum (1998): if a minimal degree of intuitive processing is taken as a necessary requirement for DMC, it could well be that conditions other than VMPC lesions may be associated with incompetence which raises questions about the desirability of deeming those patients incompetent. This may for example pertain to persons with alexithymic traits often associated with a range of different mental disorders and neurodiverse conditions—for example, autism spectrum disorder, somatoform conditions, depression, posttraumatic stress disorder, eating disorders, or a range of personality disorders (Taylor, Bagby, & Parker, 1997). Alexithymia is distinguished by deficits in emotion recognition and expression. Hence, testing for a patient's intuitive processing might be adverse for such people since they have difficulty identifying their emotions, and in verbalizing them. A question remains concerning the extent to which doubts about the reasoning skills of DMC patients are properly grounded, and whether it is desirable to put them at risk of being deemed incompetent.

Appelbaum (1998) has also raised another critical and warranted question regarding the inclusion of intuition, asking whether one could tell whether an absence of emotion indicated a lack of capacity to experience emotions or simply a lack of strong feelings about the matter at hand. It is certainly true that there are medical decisions that have no power to touch the patient on an emotional level, presumably because they are only to a minimal degree personally significant or preference-sensitive. Imagine a choice between two medications which are equally effective but have slightly different and marginal side-effects, so that the patient is likely to be indifferent, and chooses more or less randomly or on the basis of simple heuristics. In these circumstances, the proposed integrative approach towards reasoning appears too demanding; its application seems limited to medical decisions that are personally significant and to a minimal degree preference-sensitive, and so expected to touch on patients' values, needs, fears and hopes. This would surely be the case for end-of-life decisions. How then should one proceed in less pressing cases? Would it make sense to apply less restrictive reasoning capacity standards? Should one conduct the

DMC evaluation without considering a patient's reasoning, and testing only their understanding? These questions introduce the issue of risk-relativity, the idea that more or less abilities are required to deem a person capable, depending on the potential consequences of their decision (Buchanan & Brock, 1989). An integrative approach to patient's reasoning might be instructive in this regard—especially if one assumes that medical risk and personal involvement are positively related, and that the integration of intuition and analytical thinking becomes more important as the level of risk increases. With particular regard to risky instances, we wish to be sure that the patient is able to decide in his or her best interests, and this is most likely to be achieved by drawing on the complementary effects of both reasoning modes.

Assessing a patient's intuitive processing might also prove too personally intrusive, insofar as talking about one's experiences, character, values, or emotions can be an intimate matter. What if patients refuse to disclose this kind of information? Is it right to oblige them to do so? This potential intrusiveness may be a particular challenge in liberal legal contexts where people's privacy is highly cherished and a right to privacy is granted, touching as well on the more general problem of uncooperative patients. However, rather than seeking to avoid such problems by abstaining from any probing of patients' intuitive reasoning, attention must be paid to minimizing patients' feelings of violated privacy. A trustful patient-physician relationship also seems crucial in this respect. Furthermore, in taking seriously the a priori assumption of DMC, inquiries into patients' reasoning need only take place when these capacities are substantially in doubt; not every DMC evaluation will require assessors to delve into patients' inner lives in similar depth.

It seems clear that the present proposal to rethink reasoning in the context of DMC would require fundamental revision of current assessment procedures and criteria for operationalization, which goes beyond the scope of this paper and remains open to further discussion. One point is worth noting here: to the extent that the evaluator is required to react and adapt flexibly to a patient's decision-making style, there would presumably be less scope for standardization of the procedure. This in turn raises issues of transparency with regard to the evaluation and final judgment, prompting concerns about unequal treatment of similar patients by virtue of an overly flexible and individualized assessment of patients' capacities.

Finally, there may be some feasibility constraints in respect of the suggested probing of patients' reasoning or self-reflection by means of a dialogical, co-constructive engagment of patient and physician in a narrative process, principally involving restrictions of time and

resources in hectic and cash-strapped care contexts. However, given the thirty minutes required for administering the MacCAT-T (including preparation and rating), implementation of the suggested approach would seem to rely in part on practitioners' willingness and ability to step out of their usual routine for a moment to engage with the patient in an unstressed and free conversation.

Conclusion

Psychological insights into human decision-making challenge the purely analytical current understanding of the *reasoning* standard in the context of DMC evaluations. Given intuition's unique contribution to and significance for competent decision-making by virtue of its emotional import, it seems crucial to take proper account of major impairments in both analytical and intuitive reasoning. Along with its claim to respect patients' individual preferences for a certain decision-making style, the current definition and operationalization of the *reasoning* standard appear unsatisfactory. A more integrative reconceptualization of reasoning as the ability to self-reflect in the face of a particular decision—including the capacity to connect to one's emotional self—and to derive a choice from self-reflection seems a promising way of addressing these shortcomings. With regard to implementation, a dialogical and narrative approach seems worthwhile as a means of probing and enhancing patients' reasoning and, ultimately, their DMC. Many questions remain to be answered, and further research is needed to clarify these and related challenges.

7.4 Physicians' Personal Values in Determining Medical Decision-Making Capacity: A Survey Study

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Abstract

Decision-making capacity (DMC) evaluations are complex clinical judgements with important ethical implications for patients' self-determination. They are achieved not only on descriptive grounds but are inherently normative and, therefore, dependent on the values held by those involved in the DMC evaluation. To date, the issue of whether and how physicians' personal values relate to DMC evaluation has never been empirically investigated. The present survey study aimed to investigate this question by exploring the relationship between physicians' value profiles and the use of risk-relative standards in capacity evaluations. The findings indicate that physicians' personal values are of some significance in this regard. Those physicians with relatively high scores on the value types of *achievement*, *power-resource*, *face* and *conformity to interpersonal standards* were more likely to apply risk-relative criteria in a range of situations, using more stringent assessment standards when interventions were riskier. By contrast, those physicians who strongly emphasise *hedonism, conformity to rules* and *universalism concern* were more likely to apply equal standards regardless of the consequences of a decision. Furthermore, it has been shown that around a quarter of all respondents do not appreciate that their values impact on their DMC evaluations, highlighting a need to better sensitise physicians in this regard. The implications of these findings are discussed, especially in terms of the moral status of the potential and almost unavoidable influence of physicians' values.

Introduction

Evaluations of patients' medical decision-making capacity (DMC) are complex endeavours with far-reaching ethical implications in terms of patients' self-determination (Buchanan & Brock, 1989). It is widely agreed that such evaluations are ultimately based on the healthcare practitioner's clinical judgement, integrating diverse information about patients' functional abilities and mental status and about contextual and situational factors (Grisso & Appelbaum, 1998a). Furthermore, it is acknowledged that DMC judgements are achieved not on descriptive grounds alone but are tightly bound to normative considerations (Berghmans, 2001; Charland, 2001). These involve questions concerning the relevance of various mental abilities and the necessary extent of their integrity (Banner, 2012). Moreover, the eventual question to be answered is whether or not the patient in his or her current state ought to be deemed capable for making the specific decision at hand (Appelbaum & Roth, 1982; Buchanan & Brock, 1989). As a consequence, it is assumed that DMC judgements are always to a certain degree influenced by the normative climate in a society as well as by the personal value system of the healthcare practitioner who evaluates a patient's DMC.

Such personal influences are important from an ethical perspective insofar as patients may be evaluated differently depending on which physician they encounter, potentially yielding different competence judgements of similar patients and resulting in arbitrariness. Furthermore, a physician's values may impact unduly on competence judgements, reflecting unjustified paternalism and so jeopardising patient autonomy.

In his influential work The Nature of Human Values, Rokeach (1973) defines value as

> *an enduring prescriptive or proscriptive belief that a specific mode of behavior or end-state of existence is preferred to an oppositive mode of behavior or end-state. This belief transcends attitudes toward objects and toward situations; it is a standard that guides and determines action, attitudes toward objects and situations, ideology, presentation of self to others, evaluations, judgements, justifications, comparisons of self with others, and attempts to influence others* (p. 25).

Moreover, values are organised in a value system along a continuum of relative importance whereby individual differences in such value systems evolve from variations in personal, societal and cultural experiences (Rokeach, 1973).

Empirical research on DMC has been primarily concerned with patients' functional abilities; factors on the side of the evaluator have rarely been investigated. To our knowledge, there are no studies looking at the relationship between healthcare

practitioners' personal values and their DMC evaluation practice. The present study set out to explore whether or not such relationships exist, and what form they take. More specifically, the study aimed to investigate these relations with regard to the issue of risk-relativity, to establish whether or not physicians with particular values are more or less likely to use risk-relative standards in DMC evaluations.

Risk-relativity refers to the idea that, as a function of the risk-benefit profile of a certain decision, more or less stringent, or different, criteria of mental capability are required for deeming a patient competent. For example, if the treatment choice carries only a minor risk, it suffices that the patient understands the given information; whereas if a high-risk option is chosen, he or she must additionally be able to weigh the given information in light of his or her own values. Risk-relativity differs from considerations of other decision-specific factors such as the complexity of the decision. While risk-relativity calls for different standards, the complexity of a decision demands different levels of abilities which are, however, captured by consistent standards. For example, with increasing complexity, better abilities are required to understand information, but the standard remains unchanged (namely, understanding). Risk-relativity remains a matter of debate and controversy. While some authors regard considerations of risk as an inevitable feature of DMC evaluations because they seem the only reasonable way of determining thresholds for mental abilities (Buchanan & Brock, 1989; Grisso & Appelbaum, 1998a), others express great concern that risk-relativity may be a means of introducing inappropriate medical paternalism through the back door (Wicclair, 1991b). Risk-relativity is therefore an important factor in any investigation of the relationship between physicians' values and DMC evaluations because of the potential of practitioners' personal values to unduly influence risk-relative evaluations.

As a broader goal, the study seeks to provide an empirical basis for further ethical reflection on how DMC evaluations may be affected by physicians as individuals.

Method

The present investigation was part of a larger cross-sectional survey study on 'Decision-making Incapacity at the End of Life and its Assessment in Switzerland'.[41]

[41] See publication 5.

Participants

The participants under investigation formed a subsample of the abovementioned study, comprising 637 senior physicians with accredited medical specialisms and practicing in Switzerland who filled out a questionnaire in the context of the larger study and an additional questionnaire on physicians' values (inclusion of 83.5% of the larger study's participants, corresponding to a response rate of 18.3%). Participants were recruited via mail, and were offered the option of completing the questionnaire by means of either a paper-pencil version or an online link. Data collection lasted from June to November 2013.

Questionnaires

To assess physicians' attitudes towards risk-relativity, three questions were formulated. The first item, presented as a four-point Likert scale (not at all relevant to very relevant), asked physicians how relevant they considered the consequences of a decision for DMC evaluations to be, in terms of severity of risk. The following example was given to better illustrate what is meant: You apply, for example, higher standards in terms of mental abilities, if the decision has serious adverse consequences.

Box 1. Case vignettes.

Chemotherapy

A patient has to decide whether or not he wants his cancer to be treated with chemotherapy. If the patient undergoes chemotherapy, the chance of having the tumor growth stopped without recurrence will be 70%. Refraining from treatment on the other hand will likely result in death within a few months. There are no other pertinent treatment options. The patient's medical decision-making capacity is doubted and needs further examination.

In which case do you apply higher standards in terms of mental abilities for assessing medical decision-making capacity?

1. The patient chooses to undergo chemotherapy.
2. The patient chooses *not* to undergo chemotherapy (treatment refusal).
3. In both cases, I apply *equally stringent* standards in terms of mental abilities.

Assisted suicide

The same patient (from the *chemotherapy* vignette above) decided not to undergo chemotherapy (treatment refusal). Instead he asks for assisted suicide.

You are consulted to evaluate the patient's medical decision-making capacity.

Which standards must be fulfilled to deem the patient capable? (multiple answers possible)

1. I apply *more stringent* standards in terms of mental abilities as in the case of treatment refusal.
2. I apply *equally stringent* standards in terms of mental abilities as in the case of treatment refusal.
3. I must be personally convinced that assisted suicide is the best option available for the patient.

The next two questions were formulated as consecutive case vignettes, describing options with increasing severity of consequences in terms of life expectancy, from treatment consent to chemotherapy (high probability of survival) to treatment refusal of chemotherapy (high probability of death within a short time) to assisted suicide (immediate death) (see Box 1). In each vignette, physicians were asked to indicate whether and in which case (treatment consent vs treatment refusal; treatment refusal vs assisted suicide) they would apply more stringent standards in relation to mental abilities.

Moreover, in the assisted suicide vignette, an additional option was presented to directly elicit whether or not physicians would take their own stance on assisted suicide as a criterion for deeming the patient competent.

In addition, physicians were asked to indicate on a four-point Likert scale (not at all to very) to what extent they thought their own values would influence DMC evaluations.

For the assessment of physicians' personal values, a refined instrument of the extensively researched Schwartz Value Scale was used (Schwartz et al., 2012). In comparison to the original scale that measures 10 basic values (Schwartz, 1992), the refined version partitions the array of values into a finer set of 19 meaningful and conceptually distinct values (Table 3). Each value is defined by a motivational goal that serves as a guiding principle in the life of a person. For example, a person who strives transsituationally and exceedingly for pleasure and sensuous gratification—a motivating goal for this person—scores high on the value referred to as 'hedonism' by Schwartz and colleagues. Items are rated on a six-point Likert scale. The instrument has been validated in different countries and languages.

In addition to descriptive statistics, t tests were used to compare physicians' value profiles depending on whether or not they used risk-relative standards. Missing values were deleted pairwise. Significance was assigned at the 5%-level.

Table 3. 19 values of the PVQ-RR (Schwartz et al., 2012).

Value	Conceptual definitions in terms of motivational goals
Self-direction-thought	Freedom to cultivate one's own ideas and abilities
Self-direction-action	Freedom to determine one's own actions
Stimulation	Excitement, novelty, and change
Hedonism	Pleasure and sensuous gratification
Achievement	Success according to social standards
Power-dominance	Power through exercising control over people
Power-resources	Power through control of material and social resources

Face	Security and power through maintaining one's public image and avoiding humiliation
Security-personal	Safety in one's immediate environment
Security-societal	Safety and stability in the wider society
Tradition	Maintaining and preserving cultural, family, or religious traditions
Conformity-rules	Compliance with rules, laws, and formal obligations
Conformity-interpersonal	Avoidance of upsetting or harming other people
Humility	Recognizing one's insignificance in the larger scheme of things
Benevolence-dependability	Being a reliable and trustworthy member of the ingroup
Benevolence-caring	Devotion to the welfare of ingroup members
Universalism-concern	Commitment to equality, justice, and protection for all people
Universalism-nature	Preservation of the natural environment
Universalism-tolerance	Acceptance and understanding of those who are different from oneself

Results

Among the 637 participants, a majority practiced in hospitals (84.5%, n=538), while only a minority worked in a specialist practice (15.7%, n=100), family practice (3.8%, n=24) or in another field (6.4%, n=41). Most of them worked full time (72.2%, n=460), with an average career duration of 20.95 years (SD=8.279). There were more male participants (65.5%, n=417) than female (34.1%, n=217), with an overall average age of 48.24 years (SD=8.123). In terms of medical specialties, those most frequently represented were internal medicine (30.5%, n=194), anaesthesiology (15.1%, n=96), psychiatry (11%, n=70) and intensive care medicine (8.8%, n=56). The numbers of participants with missing data were as follows: risk-relativity general item (n=30); chemotherapy vignette (n=4); assisted suicide vignette (n=21); value item (n=47); no missing values for the Portrait Value Questionnaire Revised.

General and Case-Specific Attitudes Toward Risk-Relativity

On the generally formulated item, the majority of physicians indicated that the severity of consequences of a medical decision was rather or very relevant for their DMC evaluation (72.6%, n=463). By contrast, analysis of the case vignettes showed that 65.9% (n=420) in the chemotherapy vignette, and 56.5% (n=360) in the assisted suicide vignette refrained from a risk-relative standard and applied equally stringent criteria (Table 4). Almost all physicians who stated that the consequences are not at all relevant for DMC evaluations on the general item also indicated in the vignettes that they would apply equally stringent standards (chemotherapy: 92.7%; assisted suicide: 85.5%). In contrast, only half of those who regarded consequences as very relevant for DMC evaluations (on the general item) set higher

standards in the case of treatment refusal (chemotherapy vignette; 43.4%) or in cases where the patient demands assisted suicide (assisted suicide vignette: 48.5%). The other half of participants refrained—contrary to their general attitude—from a risk-relative standard, and applied equally stringent criteria (chemotherapy: 55.4%; assisted suicide: 51.5%). Only a few indicated that they would apply higher standards if the patient consented to chemotherapy (chemotherapy vignette option 1; 0.9%, n=6), and therefore, this group was excluded from further analyses (Table 4).

Table 4. Cross tabulation: General and case specific attitudes towards risk-relativity.

	General attitude towards risk-relativity				
	not at all relevant	*rather not relevant*	*rather relevant*	*very relevant*	**TOTAL**[+]
Chemotherapy					
1) The patient chooses to undergo chemotherapy.	0%*	0%*	1.4%*	1.2%*	0.9% (n = 6)
2) The patient chooses not to undergo chemotherapy (treatment refusal).	7.3%*	18%*	33.8%*	43.4%*	32.5% (n = 207)
3) In both cases, I apply equally stringent standards in terms of mental abilities.	92.7%*	82%*	64.8%*	55.4%*	65.9% (n = 420)
Assisted suicide					
1) I apply more stringent standards in terms of mental abilities as in the case of treatment refusal.	14.5%*	33.3%*	35.8%*	48.5%*	35.6% (n = 227)
2) I apply equally stringent standards in terms of mental abilities as in the case of treatment refusal.	85.5%*	66.7%*	64.2%*	51.5%*	56.5% (n = 360)
3) I must be personally convinced that assisted suicide is the best option available for the patient.	9.1%*	10.2%*	17.8%*	17.4%*	15.9% (n = 101)
TOTAL[+]	8.6 % (n = 55)	14 % (n = 89)	33.4 % (n = 213)	39.2 % (n = 250)	

[+] % within total sample.
* % within *general attitude towards risk-relativity*.

A comparison of the two consecutive vignettes shows that 43.9% (n=280) indicated that they would apply equally high standards in both vignettes (same standard for treatment consent, treatment refusal and assisted suicide), while 17.5% (n=112) indicated that they would apply risk-relative standards in both vignettes (higher standard in treatment refusal

than in treatment consent, and an even higher standard in the case of assisted suicide). Another 17.3% (n=110) indicated that they would apply equal standards in the chemotherapy vignette and risk-relative standards in the assisted suicide vignette (same standard for treatment consent and treatment refusal, with a higher standard for assisted suicide). Another 12.6% (n=80) indicated that they would apply risk-relative standards in the chemotherapy vignette and equal standards in the assisted suicide vignette (same standard for treatment refusal and assisted suicide, but a lower standard for treatment consent).

Personal Stance on Assisted Suicide

Although in the minority, some physicians did state that they would have to be personally convinced that assisted suicide was the best option available to the patient as a criterion for deeming that patient competent (15.9%, n=101; see Table 4).

Relation to Personal Values

A quarter of all physicians indicated that their own set of values rather or very much influences their DMC evaluations (26.1%, n=166). In contrast, 22.4% (n=143) said that their own values had no effect at all.

With regard to physicians' values, exploratory mean group comparisons of the answers in the vignettes yielded the following (Table 5): In comparison to those physicians who applied equally stringent criteria, physicians who used a risk-relative standard in the chemotherapy case scored significantly higher on the values of *achievement*, *power-resources* and *face*, and significantly lower on *conformity-rules* and *universalism-concern*. With regard to the assisted suicide vignette, physicians with a risk-relative approach scored significantly higher on *conformity-interpersonal*, and significantly lower on *hedonism*, in comparison to those who applied equally stringent standards. Furthermore, those who said that they must be personally convinced that assisted suicide is the best available option returned lower scores on the value of *hedonism* in comparison to those who refrained from such a standard. Correlation analysis between the general risk-relativity item and value scores yielded no significant results.

Table 5. Group mean comparisons (t-tests): Personal values and case specific attitudes.

			Chemotherapy		*Assisted Suicide*			
Value			risk-relative standard vs (option 2)	equal standard (option 3)	risk-relative standard vs (option 1)	equal standard (option 2)	personally convinced: yes vs (option 3)	personally convinced: no
	M	SD	t	p	t	p	t	p
Self-direction-thought	5.13	.565	.775	.439	-1.013	.311	-.202	.84
Self-direction-action	5.23	.618	-.302	.762	-.674	.501	.286	.775
Stimulation	3.91	.941	.406	.685	.656	.512	-1.11	.268
Hedonism	4.07	.972	.601	.548	**2.341**	**.02**	**2.874**	**.005**
Achievement	4.36	.829	**-3.161**	**.002**	-1.293	.197	1.285	.199
Power-dominance	2.95	.894	-.813	.416	-.077	.938	-.661	.509
Power-resources	2.34	.900	**-2.829**	**.005**	.116	.907	-.604	.547
Face	4.01	.917	**-2.012**	**.045**	-.916	.360	.043	.966
Security-personal	4.15	.780	-.628	.53	-.240	.810	.259	.795
Security-societal	3.97	.946	.779	.436	-1.656	.098	1.015	.31
Tradition	3.65	1.104	-.236	.814	-.933	.351	-1.079	.281
Conformity-rules	3.85	.978	**2.097**	**.037**	1.791	.074	.29	.772
Conformity-interpersonal	3.96	.882	-.856	.392	**-2.113**	**.035**	-.292	.77
Humility	4.22	.780	1.734	.083	.785	.433	-.41	.682
Benevolence-dependability	5.21	.646	-.261	.794	-1.351	.177	-.122	.903
Benevolence-caring	5.02	.686	-.456	.649	.746	.456	-.53	.597
Universalism-concern	4.75	.786	**2.604**	**.009**	1.019	.309	.498	.619
Universalism-nature	4.37	1.014	.471	.638	1.689	.092	-1.533	.126
Universalism-tolerance	4.87	.722	1.892	.059	-.042	.966	.205	.837

For t-tests centred value scores were used, each value centred around individuals' mean score across all 57 value items (recommended by S. H. Schwartz).

Discussion

The aim of the present study was to explore the relationship between physicians' attitudes towards risk-relativity and their personal values. The findings address the complex issue of risk-relativity from an empirical perspective, and point to the potential impact of healthcare practitioners' values in DMC evaluations.

In terms of risk-relativity, the obvious discrepancy between physicians' general and case-specific attitudes is noteworthy, especially in those who demonstrated a general attitude in favour of a risk-relative approach. A high proportion of those who said they would evaluate DMC with due regard to the consequences of a decision refrained from such an attitude in response to the specific case vignettes.

In the case of the chemotherapy vignette at least, this may be explained by referring to the notion of asymmetrical competence (Wilks, 1997), the observation that while a patient may be competent to consent, they may be incompetent to refuse the same treatment. Such asymmetries are likely to occur under a risk-relative standard since the severity of consequences often diverges with treatment consent or refusal. The discrepant findings may result from an unequal manifestation of this asymmetry, which is supposed to be stronger in the vignette than in the general item because, in the vignette, the different alternatives are listed next to each other. It may therefore be that the appeal of a risk-relative standard becomes less intuitive, or even counterintuitive, as soon as the asymmetry becomes evident.[42] It is not our intention to take a position for or against risk-relativity or asymmetrical competence; we wish only to show that the ambivalence around this issue in the scientific literature can also be found in clinicians (Cale, 1999; Wicclair, 1999; Wilks, 1999), and that approaches to risk-relativity may differ according to the framing of the situation.

Although there is no comparable set of options for consent or refusal to the same treatment in the assisted suicide vignette, there is still an explicit comparison of alternatives that frame the situation differently, in contrast to a situation where the two decisions are separately presented and the standards are not relatively but absolutely determined.

In general, framing effects applying to the vignettes are interesting not as limitations to the study but rather as another sort of bias that needs to be critically assessed from a moral standpoint. Is it, for example, right to apply different standards in terms of mental abilities just because one has formed a particular view of the patient because of how the situation is framed?

Despite the obvious progression of the severity of consequences—at least from a medical perspective—from treatment consent, to treatment refusal, to assisted suicide, a third of physicians are not consistent in applying a risk-relative standard. Within this progression, there are physicians who only raise the standard when it comes to assisted suicide, and others who raise the standard when the patient refuses treatment, continuing to adhere to

[42] See also publication 5.

the higher standard in respect of assisted suicide. These findings suggest that there is something more at stake than the quantifiable severity of consequences, as qualitative aspects also appear to play a role. Moreover, there would appear to be individual differences in the perception of those qualitative aspects. Some physicians lump together treatment consent and refusal, separating them qualitatively from assisted suicide; others see no qualitative difference between treatment refusal and assisted suicide but distinguish them qualitatively from treatment consent. Taken together, these results strongly indicate that DMC evaluations are far from independent of physicians' attitudes and values.

This view is additionally supported by the responses to item 3 of the assisted suicide vignette. Although in the minority, some physicians said that they must be personally convinced that assisted suicide is the best option available to the patient as a criterion for deeming the patient competent. Certainly, physicians are allowed to have different attitudes towards assisted suicide, and to refuse to offer assistance. However, it seems unduly paternalistic to deem the patient incompetent because of one's personal conviction that assisted suicide is not a good option.[43] In this case, a physician's value judgement directly and deliberately pertains to the outcome of the patient's choice, and there is agreement that DMC evaluation should never be based solely on the decisional outcome but should rather be concerned with the decision-making process (Buchanan & Brock, 1989). It remains to be explored whether such effects also exist in less controversial situations or decision-making contexts.

A closer look at physicians' values reveals that specific types of value relate to the use of risk-relative standards, and the results suggest that these relations differ with the particular situation: the values relating to a risk-relative evaluation in the chemotherapy vignette were not the same as those in the assisted suicide case. This case-specificity may also explain why there are no significant correlations between value scores and the general risk-relativity item.

Regarding consent or refusal to chemotherapy, those physicians who applied a risk-relative standard (i.e., set higher standards in terms of mental abilities in the case of treatment refusal) were characterised by relatively high power and achievement values, which serve self-enhancement with a focus on social esteem.

Persons with high achievement values emphasise the active demonstration of competence or the pursuit of success as judged by the normative standard in a culture, whereas persons with high power values emphasise the attainment or preservation of a dominant position to

[43] See also publication 5.

obtain social approval (Schwartz, 1992). In terms of power values, risk-relative evaluations have been shown to be prevalent specifically in those physicians who strive for maintenance and protection of their own prestige, and for control over events, through their social and material resources. Although there is no significant effect with regard to the subtype *power-dominance*—the power to constrain others to do what one wants—the results may nonetheless be seen to support the concern that risk-relativity is used to introduce unjustified medical paternalism through the back door. This suggestion is grounded on the assumption that those physicians who strive for power, prestige and socially acknowledged success within their profession may see their personal values especially threatened if patients refuse a medically indicated treatment, and are therefore more likely to assess DMC as risk-relative to raise the standard for deeming the patient competent in cases of treatment refusal.

By contrast, physicians who strongly emphasise equal opportunity and equal treatment for all—a highly self-transcending value—tend to refrain from risk-relative standards, applying equally stringent criteria regardless of the decision. The same is true for those physicians who value conformity to laws, rules and authority, as if the use of equal standards were seen as the right or expected way to assess DMC.

Concerning assisted suicide, hedonism plays a role here to the extent that those who place high value on pleasure also tend to apply equally stringent standards in both decisions—against chemotherapy and for assisted suicide. This may be explained by a strong empathy for patients' wishes to avoid any enduring suffering by ending their own lives. For this reason, they may choose not to raise the standard for deeming a patient competent in the case of assisted suicide. Additionally, these physicians are less likely to say that they must be personally convinced of the appropriateness of assisted suicide as a criterion for deeming the patient competent.

On the other hand, those physicians who emphasise restraint in respect of actions or inclinations that upset others are more likely to apply risk-relative standards, as if the use of equal standards in the case of assisted suicide was socially undesirable, likely to upset others, and therefore a threat to the values of those physicians.

While the results of this study indicate that risk-relativity may indeed be problematic to the extent that it introduces unjustified medical paternalism, it would be premature to reject risk-relative standards solely on the basis of these empirical findings—first, because the appropriateness of risk-relativity depends primarily on the conceptualisation of DMC; and second, because the present findings are preliminary, further studies would be needed to

replicate the present findings, with regard to other kinds of medical decisions as well. To overcome the limitations associated with survey studies, it may also be worthwhile to deploy other research methods that account better for clinicians' actions in real life.

From an ethical standpoint, it seems important to consider the moral status of the influence exerted by physicians' values. Is there, for example, a difference between deliberately taking one's personal stance on assisted suicide as a criterion for DMC and being more implicitly driven by one's personal inclinations? Does it make a moral difference whether self-enhancing or self-transcending values impact on capacity evaluations? And what about different sorts of self-enhancing values—does it, for instance, make a difference whether a judgement is influenced by hedonism as distinct from a striving for power? Where should we draw the line in judging whether an influencing factor is morally permissible or not?

It further remains in question how best to handle these physician-specific factors. Since a total ban on such influences seems impossible, we propose that healthcare practitioners' awareness of the impact of their personal values should be heightened, and that self-reflection should be encouraged with regard to the moral appropriateness of these influences. The fact that a quarter of participants in this study did not appreciate the potential impact of their values highlights a need to better sensitise physicians in this regard.

Ultimately, the evaluating physician must justify his or her own judgement, thereby also taking his or her own values into account, and make it intersubjectively comprehensible.

Conclusion

The inherent normativity of DMC is of concern for theorists of ethics and others who seek to articulate appropriate criteria in this context and for every clinician who is involved in DMC evaluations. Though guided by existing standards, capacity judgements are in the end discretionary, as the evaluator alone eventually determines whether or not it is legitimate to intervene on paternalistic grounds.

Such judgements necessarily involve values which render them less objective and more susceptible to external and potentially inappropriate influences. It has been shown that such influences are not always deliberate but evolve tacitly from physicians' personal inclinations and values, affecting the stringency of standards required for DMC, including in some cases the use of risk-relative standards.

This evokes concerns about arbitrariness or even undue and disguised paternalism. At the same time, it seems difficult to totally circumvent any influence of physicians' personal

values on DMC evaluations and final competence judgements. It remains to be asked to what extent such influences are morally permissible, and at what point they clearly signal unjustified paternalism.

There may be no other choice than to accept that, within the evaluation, there is always a personal bias that renders the competence judgement specific to the patient and to the dyad of patient and physician.

Further research is needed to replicate and extend the empirical findings to other medical situations, and to other aspects of DMC evaluations, and to reflect on the moral appropriateness of physicians' personal values within those evaluations.

7.5 Medical Decision-Making Capacity: Knowledge, Attitudes, and Assessment Practices of Physicians in Switzerland

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Abstract

OBJECTIVE: Decision-making capacity (DMC) is an indispensable prerequisite for patients' informed consent and therefore directly related to the right to self-determination. In view of this ethical implication, valid and reliable assessment of DMC is essential to best practice. In general, and with particular regard to the Swiss context, little is known about healthcare practitioners' knowledge of and attitudes to the concept of DMC, or about their assessment practice. The present study aims to close this gap. METHOD: A randomised representative sample of 3,500 physicians, including all specialisms and from all parts of Switzerland, were contacted by mail and invited to complete a survey questionnaire, which was specifically designed for the purpose of the study.

RESULTS: A total of 763 questionnaires were included for analysis (response rate: 22.15%). Physicians diverged in their general understanding of DMC as either a *dichotomous* or a *gradual concept*, and in relation to the conceptual challenges of *decisional relativity* and *risk-relativity*. Along with cognitive abilities, emotional, intuitive, or evaluative factors were acknowledged as important *criteria*. DMC was most often assessed *implicitly*: explicit assessments, if conducted, depended mainly on *unstructured interviews*. A discrepancy was identified between physicians' perceptions of *responsibility* and *qualification*, indicating a related need for more *guidance* and *training*. CONCLUSION: The conceptual and practical challenges of DMC are far from being resolved. There is a clear need for more guidance in this area in the form of guidelines, tools, and training.

Introduction

Decision-making capacity (DMC) is among the prerequisites for valid consent to medical treatment. From an ethical perspective, DMC judgements reflect the tension between the moral duty to respect the autonomy of the individual who is capable of making his or her own decision and the need to protect decisionally incapable persons (Buchanan & Brock, 1989). Evaluations of DMC seek to balance these different moral concerns, and to set the course for appropriate and responsible action. The issue is especially relevant in the case of vulnerable persons, such as those with cognitive and mental impairments or in precarious situations for example, end of life situations that may often involve existential, medical-ethical decisions (Trachsel, Mitchell, & Biller-Andorno, 2013). It seems essential, then, to first seek clarity with respect to the definition and constitutive elements of the concept, and second, to be able to reliably and validly assess DMC in vulnerable patients. From a conceptual perspective, a range of challenges arise (Trachsel et al., 2014a). One very general issue concerns the distinction between dichotomous and gradualist notions of DMC, both of which seem valid from different viewpoints. If emphasis is put on the actions guiding clinical judgment, it is preferable that DMC be seen as either present or absent, with a clear threshold. However, if emphasis is placed on underlying mental abilities, which can in turn be more or less intact, a gradualist understanding may be more appropriate (Buchanan & Brock, 1989).

In terms of mental abilities, the delineation of relevant criteria is also conceptually challenging. The following four criteria have been proposed (Appelbaum & Grisso, 1995): (1) *evidencing a choice* refers to the ability of the patient to communicate a choice; (2) *understanding* refers to the ability to comprehend treatment-related information, such as information about the present disorder, treatment options, and related risks and benefits; (3) *appreciation* refers to the ability to appreciate the nature of the disorder, and the possibility that treatment could be beneficial (which is distinct from the understanding standard in that it requires the patient to apply the information to his or her own situation); and (4) *reasoning* refers to the ability to manipulate information rationally, using logic to compare the risks and benefits of treatment alternatives. However, it remains a matter of debate as to whether these criteria are appropriate and sufficient: they are, for instance, criticised for being unduly focused on cognitive aspects (e.g., Charland, 1998b; Cox White, 1994).[44]

[44] See also publication 2 and 3.

There is more agreement around the challenge of decisional relativity. It is widely accepted that DMC is assessed as a function of a particular *decision* or *situation*, which implies that a patient may be capable of making a particular treatment decision but is less capable of assessing another (Buchanan & Brock, 1989). DMC may vary over *time* due to fluctuating mental abilities (Trachsel et al., 2014b), and the notion of relativity may also apply to the *risk* that accompanies a certain decision. A risk-relative assessment of DMC means an evaluation of capacity with due consideration of the risk-benefit profile related to a certain decision, using different or more stringent criteria in terms of mental abilities according to the level of risk associated with the patient's choice. For example, if the treatment choice carries only a minor risk, it may be sufficient that the patient understands the given information; if a high-risk option is chosen, s/he must additionally be able to weigh the given information in light of his or her own values. Taking risk-relativity into account in evaluating DMC is controversial and constitutes one of the most complex challenges to the concept (e.g., Brock, 1991; Wicclair, 1991b).

In addition to these conceptual aspects, DMC assessments are also challenging from a practical perspective, involving questions of how to translate conceptual concerns into a feasible, valid, and reliable assessment procedure, and how such procedures should optimally be formulated.

Scholars have taken steps both to clarify the conceptual challenges and to address practical issues by, for example, developing and validating standardised assessment tools (for an overview see Lamont et al., 2013a). Additionally, DMC has been investigated in different patient populations (Kim, 2010). By contrast, relatively little is known about the assessing clinicians or their knowledge, attitude and approach to the concept and the assessment of DMC. However, the few existing studies focused primarily on these aspects have shown that misunderstandings and knowledge deficits are prevalent among healthcare practitioners, indicating that continuing education and training is needed in this area (Lamont et al., 2013b). At present, there are no existing studies that provide information on how physicians in Switzerland approach the conceptualisation and evaluation of DMC. For this reason, the aim of the present study was to augment this line of research in an attempt to shed light on the situation in Switzerland. The following clusters of research questions guided the survey (see Box 2):

Box 2. Research questions.

(1) How do physicians perceive their *responsibility* and *qualifications* for conducting DMC evaluations?
What is the current state of physicians' *attitudes and knowledge* of DMC in terms of general *conceptual understanding*, relevant *mental abilities*, *decisional relativity*, and *risk-relativity*?

(2) How is DMC dealt with in *clinical practice*? Which *patient behaviours* and patient groups challenge DMC? Which *complicating factors* do physicians encounter? And what kinds of *interventions* and *strategies* do physicians use to enhance patients' capacity?

(3) What kind of DMC *assessment procedures* do physicians conduct?

(4) Do physicians request DMC assessment *tools* and official *guidelines*, or do they seek more extensive *education* and *training*?

Methods

Study Design, Procedure, and Sample

The present survey was part of the study „Decision-making incapacity at the end of life and its assessment in Switzerland", funded within the *National Research Programme NRP 67 End of Life of the Swiss National Science Foundation*, and conducted in cooperation with the *Swiss Academy of Medical Sciences (SAMS)*. The study protocol was approved by the ethical review committee of every Swiss canton.

The research questions were addressed within a representative cross-sectional survey of physicians in Switzerland. The main survey questionnaire was developed specifically for the purpose of the present study. At each stage of the project, a multi-disciplinary advisory board comprising physicians, psychologists, ethicists, and lawyers was consulted (see Acknowledgements section).

Hard copies of the survey questionnaire were sent by mail. Participants had the option of filling in a paper-and-pencil version of the questionnaire or using a link to an online version. Data collection lasted for six months from June to November 2013. As a reward for participation, all respondents were included in a prize draw for 15 book vouchers of 100 Swiss Francs.

The study was conducted among senior physicians practising in Switzerland as accredited medical specialists. A randomised representative sample of 3,500 physicians, including all specialisms and from all parts of Switzerland (German, French, and Italian), was drawn by the *Swiss Medical Association FMH*, corresponding to approximately 11% of physicians in Switzerland (Hostettler & Kraft, 2014). Fifteen subjects were not included, either because they were on the project advisory board or had taken part in the pilot study.

Survey Questionnaire

A first version of the survey questionnaire was developed, based on the research questions of the present study. This first version was discussed within the advisory group, the central ethics committee of the SAMS, and in two focus group meetings, with general practitioners, psychiatrists, and neurologists. After revision, a second version was discussed with a biostatistician and again presented to the central ethics committee of the SAMS. After a further (second) revision, the third version of the questionnaire was used for a pilot study among 86 Swiss physicians, from every specialism, in German-speaking Switzerland. The comments and suggestions of these respondents formed the basis for a third revision of the questionnaire, which led to the final version used in the main survey. This final version was then translated from German to French by a professional translator from the SAMS. Physicians from the Italian-speaking part of Switzerland could choose to fill in either the German or French version of the survey (questionnaire versions are available on request from the authors).

Statistics

In addition to descriptive statistics, nonparametric testing was used to compare physician groups (Mann-Whitney Test) or variables (Wilcoxon Signed-Ranks Test), or to detect correlations (Spearman). Significance was assigned at the five percent level. Data were analysed using SPSS 19.

Results

The questionnaire was completed by 772 physicians, which corresponds to a response rate of 22.15%. Women showed a response rate of 25.87%, and the rate for men was 20.46%. The response rate was 23.32% among German-speaking participants, and 19.08% among French-speaking participants. The majority responded via the paper-and-pencil version (90.5%); only 9.5% responded online. Since physicians who did not work as clinicians were excluded (n=9), analysis was conducted with a final sample of 763. Table 6 shows the socio-demographic variables of the sample.

Table 6. Socio-demographic variables (N=763).

		Survey sample	Swiss physician statistics	
Age (in years)		M=48.2 (SD=8.03)	M=48.8	
Sex	female	33%	38.6%	
	male	66.3%	61.4 %	
Field of practice	general practice	4.1%	outpatient setting:	52.8 %
	specialist practice	16%	inpatient setting:	45.5%
	hospital	83.7%	other:	1.7%
	other	5.9%		
Level of employment	full-time	27.1%	36%	
	part-time	72.1%	64%	
Clinical experience (in years)		M=21 (SD=8.14)	(no data available)	

M=mean, SD=standard deviation; FMH physician statistics 2012/2013 (Hostettler & Kraft, 2014; Kraft & Hostettler, 2013).

Responsibility and Qualification

In terms of responsibility and qualification, the results yielded the following crosstable (Table 7), showing a difference on these two aspects. In essence, 35.8% (n=167) of those who indicated that they feel *very responsible* for assessing DMC (61.3%, n=468) also felt that they were *surely qualified enough* for so doing.

Table 7. Cross tabulation: Responsibility and qualification for conducting DMC evaluations.

		Qualification				
		not qualified enough	*rather not qualified enough*	*rather qualified enough*	*surely qualified enough*	**TOTAL**[+]
Responsibility	*not responsible*	72.2%*	27.8%*	-	-	2.4%
	rather not responsible	11.1%*	73%*	14.3%*	1.6%*	8.3%
	rather responsible	1.9%*	31.8%*	65.4%*	0.9%*	27.7%
	very responsible	0.2%*	8.1%*	55.9%*	35.8%*	61.3%
	TOTAL[+]	3.3%	20.4%	53.7%	22.3%	

* % within gradation of *responsibility*.
[+] % within total sample.

Additional mean rank comparisons (Mann-Whitney tests) found that psychiatrists and psychotherapists not only feel more *responsible* ($p < 0.001$) but also more *qualified* ($p < 0.001$) than other specialists. Child and adolescent psychiatrists, however, only feel significantly more *responsible* ($p < 0.05$).

A Spearman correlation analysis showed (although with a small coefficient) that the more experienced physicians are, the more qualified they perceive themselves to assess DMC ($r_s = 0.15$; $p < 0.001$; one-tailed).

Attitudes and Knowledge

Asked to indicate whether DMC is a *dichotomous concept* (DMC yes/no) or a *gradual concept* (DMC more or less), a minority favoured the dichotomous notion (22.4%, n=171), but most selected a gradual conception of DMC (73.9%, n=564). A few felt indecisive with respect to this question (3.3%, n=25).

Concerning criteria for DMC with respect to *mental abilities*, the classical cognitive standards (*understanding, appreciation, reasoning*, and *evidencing a choice*) were considered most important—specifically, more important than engaging emotionally and intuitively in the decision-making process, and more important than reasoning about the given information in the light of one's coherent set of values ($p < 0.001$, Wilcoxon Signed-Ranks Test). The non-cognitive factors were nevertheless regarded as *rather* or *very relevant* by most physicians, including *emotional participation* (69.1%, n=527), reference to one's *biography, experiences*, and *intuitive knowledge* (71.2%, n=543), and reference to one's *values* (89.2%, n=681).

Since other factors besides knowledge about patients' mental abilities contribute to DMC evaluations (Grisso & Appelbaum, 1998a), physicians were also asked to indicate to what extent these may have an impact. These factors are listed below in descending order of importance, with percentage and number of physicians who quoted the factors as *rather* or *very important*: *psychopathological status* (84.5%, n=644); *medical context*, for example, urgency of treatment (75%, n=572); *complexity of treatment alternatives*, for example, risks and benefits (74.3%, n=567), *information/statements of patient's next of kin* (69.7%, n=532); *somatic status* (62.1%, n=474); *therapeutic relationship* with the physician (52.6%, n=401); *social context*, for example, extent of patient's social support (50.3%, n=384); and *physician's own set of values* (26.5%, n=202).

A vignette was presented to investigate whether or not physicians assess DMC relative to the specific decision at hand (*decisional relativity*). The scenario in question involved

obtaining consent to two different interventions that were discussed during the same consultation: (1) an adjustment of medication, and (2) a minor surgical intervention. The results showed that 58.6% (n=447) conducted discrete DMC assessments for each of the two interventions, whereas 40.2% (n=307) evaluated DMC only for the first intervention and extrapolated to the second intervention from this first judgement of DMC.

In terms of *risk-relativity*, a high proportion of physicians indicated, on a generally formulated item, that severity of consequence of a medical decision is *rather relevant* or *very relevant* for how they evaluate DMC (73.7%, n=562). By contrast, the analysis of the risk-relativity case vignette (see Box 1, *chemotherapy* vignette) showed that almost as many did not consider risk-relativity, and would apply equally stringent criteria in terms of mental abilities both in cases of consent to or refusal of chemotherapy (66.8%, n=510). Only 31.7% (n=242) demanded more stringent standards in the case of treatment refusal, which is considered to be the more risky option. Furthermore, almost all physicians who stated that the consequences of a medical decision are *not at all relevant* for DMC evaluations on the general item also indicated that they would apply equal standards for consent to treatment and treatment refusal in the vignette (92.2%, n=59). Conversely, less than half of those who regarded consequences as *very relevant* for DMC evaluations on the general item applied higher standards for treatment refusal in the vignette (41%, n=125). Of those physicians, 58% (n=177) did not conform to risk-relativity.

Another vignette, on assisted suicide, yielded comparable results (Box 1, *assisted suicide* vignette). Here, a majority of physicians applied equally stringent criteria in both cases (57.9%, n=442). Only 36.2% (n=276) asked for higher standards concerning mental abilities in the case of assisted suicide in comparison to treatment refusal (forgoing chemotherapy). Moreover, 16.4% (n=125) stated that they would have to be personally convinced that assisted suicide was the best available option for the patient as a criterion for deeming the patient capable.

Clinical Practice

Physicians were asked to indicate to what extent different *patient behaviours* raise the question of DMC. These behaviours are listed in descending order, with percentage and number of physicians who would *in most cases* or *always* be alerted by the behaviour: a patient is at immediate risk of harming himself or herself or others (87.3%, n=666); a patient makes a decision which is incomprehensible to the physician, for example, if he or she demands assisted suicide in the case of a treatable condition (81.5%, n=622); a patient

repeatedly changes his or her mind concerning the decision (68.9%, n=525); a patient is desperate and consents immediately and uncritically to every treatment that has been proposed to him or her (64%, n=488); a patient communicates that he or she does not care about the decision (63.3%, n=483); a patient cedes every treatment decision to the attending physician or to another person, because he or she does not feel confident to make the right decision (60%, n=458); and a patient does not agree with the physician's treatment recommendation (43.3%, n=330).

With regard to *patient groups*, a variety of diagnoses and conditions were presented that are known or expected to be associated with decision-making incapacity, and physicians had to state how often they assess DMC *in more detail* for each patient group. The conditions are listed in descending order, with percentage and number of physicians who examine DMC either *often* or *always* in more detail: *healthy elderly persons* (44.9%, n = 343); *patients at the end of life* (44.4%, n=339); *mild cognitive impairment* (44%, n=336); *Alzheimer's disease* (40.2%, n=307); *medical inpatients* (34.7%, n=265); *unipolar depression* (27.6%, n=210); *schizophrenia* (24.7%, n=189); *Parkinson's disease* (24.6%, n=187); *learning disability* (21.8%, n=166); and *glioma* (16.7%, n=128).

Tables 8 and 9 show which among a given set of *complicating factors* physicians regard as particularly challenging for DMC evaluations (Table 8), and which *intervention strategies* for enhancing patients' DMC they find relevant as well as feasible in everyday practice (Table 9).

Table 8. Complicating factors in DMC evaluations.

Cases of marginal capacity or a 'grey area' case between obvious capacity and obvious incapacity	69.1%	(n=527)
A very complicated ethical situation	54.5%	(n=416)
Chaotic/ conflicting family situation	46.8%	(n=357)
Patient factors (e.g., lack of willingness to cooperate)	37.5%	(n=286)
Legal situation unclear	24.8%	(n=189)
Disagreement with other treating physicians or the care team	23.6%	(n=180)
Unclear how to apply risk/benefit consideration into the final evaluation	22.7%	(n=173)
None of the mentioned aspects	0.5%	(n=4)

Table 9. Strategies for enhancing DMC: Importance and feasibility in every day practice.

	Considered as relevant strategy	Implementation mostly feasible	Implementation not or restricted feasible
I defer the capacity evaluation to a later point in time if the patient appears in bad shape.	88.1% (n=672)	38.3% (n=292)	49.8% (n=380)
I align the disclosed information to patients' needs (e.g., additional written information, diagrams and illustrations, translations).	97.1% (n=741)	68.5% (n=523)	28.6% (n=218)
I change medication which might influence patient's mental abilities.	82.7% (n=631)	26.9% (n=205)	55.8% (n=426)
I encourage the patient to discuss the upcoming decision with a close person.	97.1% (n=741)	76.3% (n=582)	20.8% (n=159)
I give the patient the chance to be accompanied by someone close.	96.6% (n=737)	78.8% (n=601)	17.8% (n=136)
I especially make sure that the dialogue takes place in a relaxed and comfortable atmosphere.	98.0% (n=748)	78.6% (n=600)	19.4% (n=148)
I acknowledge and discuss psychological aspects like anxiety and avoidance tendencies, or carry out short psychotherapeutic interventions.	90.1% (n=688)	38.4% (n=293)	51.7% (n=395)

Assessment Procedure

Physicians were asked to indicate how often they evaluate DMC *implicitly*, *explicitly* or *in consultation* with specialised colleagues (Table 10). Analysis shows a significant mean rank difference between the implicit and explicit approaches, with the former being more frequent ($p < 0.001$; Wilcoxon Signed-Ranks Test). Moreover, explicit assessments are in most cases never (38.6%; n=200) or rarely (22%; n=114) disclosed as such to the patient.

Physicians who evaluate DMC *explicitly* apply the following methods: *unstructured interview* with own situationspecific questions (92.8%, n=476); *semi-structured interview* with partly predetermined questions (8.6%, n=44); *standardised interview* with precisely determined questions (7%, n=36); *questionnaire or written test* (15%, n=77); and *non-written test procedure* (6.4%, n=33).

A closer look at the instruments which physicians listed in an open-ended format revealed that they primarily use tools that were originally designed for dementia assessments, of which the most prominent named in this survey is the *Mini Mental State Examination* (Folstein, Folstein, & McHugh, 1975). Instruments which are specifically designed for the assessment of DMC are used by only a few physicians (2.5%, n=15), and most have *never* heard of such specific instruments as the *Mac Arthur Competence Assessment Tool for*

Treatment (72.3%, n=552; MacCAT-T, Grisso & Appelbaum, 1998b); the *Aid to Capacity Evaluation* (77.2%, n=589; ACE,, Etchells et al., 1999); and *Silberfeld's Competence Tool* (84%, n=614; Fazel, Hope, & Jacoby, 1999).

Table 10. Frequency of implicit and explicit DMC evaluations and of referrals.

	often or ***always***
Implicit within the scope of the regular consultation	63.5% (n=484)
Explicit extra time and space during the consultation	36.6% (n=279)
Referral consultation of specialized colleagues	51.1% (n=390)

Demand for Assessment Tools, Guidelines, and Training

Despite physicians' lack of knowledge about and actual use of DMC *assessment tools*, most physicians indicated an interest in such instruments. More than half of physicians would appreciate a certain form of standardisation (65.8%, n=502), and *official guidelines* and more extensive *training* in systematic DMC evaluations were also clearly considered useful. However, approximately a third of all responding physicians indicated that they would not use any of the proposed tools (32%, n=244) (see Table 11).

Table 11. Request for guidance: Assessment tools, guidelines, and training.

Assessment tools (multiple answer options)			**Guidelines**	**Training**
Semi-structured interview with partly predetermined questions	40.9% (n=312)	*not at all useful*	4.7% (n=36)	0.7% (n=5)
Standardized interview with precisely determined questions	25.7% (n=196)	*rather not useful*	10% (n=76)	4.2% (n=32)
Questionnaire or **written test**	19.4% (n=148)	*rather useful*	46.9% (n=358)	41.4% (n=316)
Non-written test procedure	15.2% (n=116)	*very useful*	36.7% (n=280)	52.8% (n=403)
None of the mentioned aids	32% (n=244)			

Discussion

The aim of the present study was to gain more insight into the attitudes, knowledge, and assessment practices of physicians in Switzerland with regard to DMC. The survey yielded wide-ranging results, among which particular elements deserve further attention as they highlight unresolved conceptual challenges or point to areas requiring further improvement, especially from a practical or policy perspective.

In general, the survey demonstrates that the concept of DMC and its assessment, far from being trivial, is an issue of major importance. This is reflected, first, in the discord concerning any general conceptual understanding. It is reasonable to say that DMC is both a dichotomous concept and something gradual. DMC evaluations are challenging because they require the evaluating physician to assess characteristics of the patient which are gradual in nature and to then integrate them in a clear action-guiding judgement.

With respect to patient characteristics, the survey results indicated that physicians in Switzerland have a more nuanced understanding of relevant mental abilities than is suggested by the prevailing academic account. As well as understanding the relevance of cognitive abilities, they also acknowledge the importance of emotional, intuitive, and evaluative processes. This finding, together with theoretical arguments for the inclusion of non-cognitive elements, points to the need for further reflection on how to systematically incorporate these elements into DMC assessments.[45]

Furthermore, the results show that physicians in Switzerland agree with experts in the field that various factors beyond knowledge of patients' mental abilities contribute to judgements about DMC. Of particular interest in this regard is the impact of the physician's own set of values: a quarter of all participants regarded their values as rather or very important. This may be positively interpreted as a critical awareness of personal biases. Experts in the field generally recognise that DMC evaluations are inherently normative and, therefore, never totally objective – a fact that makes DMC evaluation even more complex and, perhaps, susceptible to unjustified medical paternalism (Charland, 2001). Responses to the case vignette on assisted suicide allude to that problem. Though in the minority, there were physicians who said that they would have to be personally convinced that assisted suicide was the best option available for the patient as a criterion for deeming the patient capable. Certainly, physicians are allowed to have different attitudes towards assisted suicide and to refuse assistance; however, it seems unduly paternalistic to deem

[45] See also publication 3.

the patient incompetent because of one's personal convictions that assisted suicide is not a justifiable option. In this case, physicians' values pertain directly to the outcome of the patient's choice, and there is agreement that DMC evaluation should not be based on the decisional outcome but rather on the decision-making process (Buchanan & Brock, 1989).

In terms of risk-relativity, the outcome also plays a role, but in a different sense, determining the requirements for patients' mental abilities in regard to the decision-making process. It goes beyond the scope of this article to discuss whether or not risk-relativity is appropriate, but physicians' attitudes indicate that this is indeed a very complex issue. A discrepancy was found between physicians' general attitude towards risk-relativity and their respective attitudes within a specific situation. A high proportion of those who would evaluate DMC at least in part on the basis of consequences arising from the patient's choice refrained from applying that attitude in response to the specific case vignette. One possible explanation for this result might be that the asymmetry (the patient is competent to consent, but incompetent to refuse treatment), which in risk-relative assessments appears somehow counterintuitive, was much more obvious in the vignette (Wilks, 1997). Further analyses and discussion of risk-relativity, especially in relation to physicians' personal values, are presented elsewhere.[46]

In terms of decisional relativity, it has been shown that almost half of all participants do not agree with the statement that DMC is dependent on the specific decision. However, it remains unclear whether this is due to a knowledge deficit or to concerns about feasibility.

Looking at physicians' evaluation practices with regard to different patient groups, it is worth mentioning that they do conduct detailed DMC assessments relatively often with healthy elderly persons and patients at the end of life. The comparable high scores may be related to the high prevalence of such patients in clinical practice and not strictly to the specific characteristics of patients; because of a lack of precision in the question, this cannot be conclusively confirmed. Nevertheless, the results indicate that these patients are affected by incompetence, and that more research is needed, especially as patients in these categories are somewhat neglected in the current DMC literature. One question of particular interest concerns the extent to which the a priori assumption of competence implicitly turns into a default presumption of incompetence in such patient groups. One of the most intriguing results of this survey, which has important policy implications, is the finding of a discrepancy between physicians' felt responsibility for conducting DMC evaluations and their qualification for the task, in combination with a related request for

[46] See publication 4.

more guidance in this area in form of official guidelines, continuing education and training, and/or assessment tools. It appears that physicians in Switzerland currently apply their own rules of thumb, acquired over time and perhaps proven to be clinically appropriate, but also evoking feelings of uncertainty. The high frequency of implicit assessments and the use of unstructured interviews with physicians' own situation-specific questions may be seen to support such an explanation. In terms of guidelines, education, and training, it would seem important not only to introduce physicians to the complex conceptual challenges around DMC, but also to remedy obvious knowledge deficits concerning existing assessment tools, and to sensitise and train them in handling practical challenges regarding how to deal, for example, with complicating factors, or how to effectively enhance patients' DMC.

Finally from an ethical point of view, further reflections on the moral dimensions of DMC evaluations seem crucial. Although clarity with regard to relevant criteria for DMC as well as valid and reliable assessments of patient characteristics are important, they do not give a concluding answer to the question of whether or not the patient is competent. This rests eventually on a normative judgement that includes a weighing of moral principles, and thus, relies on values and norms pertaining not only to the society at large but also to the individual evaluator.[47] Therefore, further reflections are needed on the moral status of such influencing factors, and the way physicians may be supported in arriving at a final judgement.

Limitations

In light of the response rate of 22.15%, the representativeness of the sample is clearly restricted. Although the sample characteristics are, in most regards, comparable to those of the population of physicians in Switzerland (Hostettler & Kraft, 2014), there is a clear over-representation of hospital physicians. In terms of medical specialisms, anaesthesiologists, surgeons, and neurologists are over-represented, and general medical practitioners are clearly under-represented. Moreover, self-selection may also have been a relevant factor to the extent that physicians with a particular need or interest in the topic were more likely to respond. It follows that an overestimation, specifically in terms of desired guidance, cannot be ruled out.

[47] See also publication 4.

Conclusion

The conceptual and practical challenges of DMC are far from being resolved. There is a clear need for more guidance in this area in the form of guidelines, tools, and training. To this end, further discussion and education would be desirable within the concerned medical associations and organisations.

8 Integration, Discussion, and Conclusion

The five publications above, originating in the context of the present dissertation, approach the concept of decision-making capacity from different perspectives. They shed light on existing challenges, clarify ambiguities, and offer new insights. They also strive for a nuanced and comprehensive picture of competence by tackling basic conceptual issues as well as offering in-depth analysis of specific aspects. In so doing, they broaden the scope of analysis, potentially adding further complexity to the concept. In the following sections, an attempt will be made to integrate the accumulated insights under the three themes of *normativity, criteria,* and *assessment,* elaborating how the intricacy of decision-making capacity in the face of clinical reality may adequately be handled by suggesting measures in support of clinicians.

8.1 Normativity

Analyses of the relevant literature have confirmed the existence of different understandings of the moral dimension of decision-making capacity, in which competence is conceived of as either *independent* or *constitutively influenced* by the balancing of moral values. This distinction is further and intimately related to the conception of competence as either an *inherent ability* or an *ethical judgment*.

To conceive of competence as an independent inherent ability is to align with the doctrine of informed consent, as well as with a theory of personal autonomy and, apparently, with the beliefs of clinicians. It has been shown that the majority of physicians in Switzerland conceive of decision-making capacity as a gradual concept, implying that, in their minds, competence is associated with a mental ability rather than a judgment. Against this, other protagonists in the field, as well as authorities, embrace the idea that competence is a judgment based on the balancing of moral values, as reflected in their advocacy and use of risk-relative standards. Additionally, physicians in Switzerland indicate that the consequences of a treatment decision matter, influencing how stringently they apply standards. To that extent, there seems to be a disconnect between physicians' conception of competence as a gradual notion, implying an inherent ability, and their risk-relative assessment practice, signifying a different understanding of competence as an ethical judgment. In this sense, practical recommendations and actual evaluations appear to diverge from an ideal understanding of competence—a gap that is apparent in the literature, recognizable among clinicians, and clearly responsible for much confusion.

In practice, it is impossible to sustain the idea that decision-making capacity is an independent inherent ability, given the power of moral intuitions, the ambiguity and insufficiency of a theory of autonomy, the axiomatic gatekeeping function of competence in the legislation, and the requirement of meaningful thresholds. It follows that to conceive of competence as an ethical judgment is not merely a matter of right and wrong but of the impossibility of sustaining a conception of decision-making capacity other than as an ethical judgment.

It has been demonstrated that evaluations of decision-making capacity are not value-free. First, substantive judgments of a patient's values, emotions, and beliefs play a significant role in evaluations of competence, at least implicitly (Freyenhagen & O'Shea, 2013). Second, physicians' personal values impact *(*mostly tacitly*)* on competence evaluations in the use of risk-sensitive standards. The elimination of such influences seems impossible; their negation seems insincere, unconstructive, and even morally objectionable, making it imperative to acknowledge the inherent moral dimension of decision-making capacity. To conceptualize competence as an ethical judgment is to better capture real conditions, although this, in a way, is to subvert the legal doctrine of informed consent. It therefore seems promising to adopt a dialectical approach between the two positions, which together entail a circular argument.

Moreover, instead of rigid and extreme positions that reduce risk-relativity or substantive criteria to unwarranted and disguised paternalism, a more differentiated account becomes possible if competence is conceived as an ethical judgment, addressing the question of whether or not paternalistic intervention is justified in a particular situation. This opens a space for reflection on the conditions of and distinctions between an adequate and inadequate balancing of moral values, as well as on measures to prevent the latter. Awareness of the impact of values—societal or personal—is a first and necessary step toward these ends; the fact that one physician in five lacks this awareness clearly indicates a need for better education. Further steps should encompass a critical, moral appraisal of these influences, along with documentation of arguments for judged incompetence, and engagement in dialogue to check its contestability.

8.2 Criteria

Moral intuitions on the part of the evaluator play an essential role in any determination of competence. Thorough evaluation of a patient's medical decision-making capacity is initiated on foot of a more or less elaborated intent to protect the patient. The sources of

these moral intuitions are presumably diverse, including patients' characteristics (appearance, behavior, mental state and functions) as well as knowledge about their personality, values, biography, medical history, and so on.

A core feature of intuition is its holistic grasp of situations, evaluating singular items of information not in isolation but in relation to each other. To that extent, doubts about a patient's competence are likely to form in view of the entire person and the integration of diverse attributes, particularly in instances where capacity-undermining influences are subtle and less obvious, as in so-called "grey zone" cases. Of particular relevance in this regard are the patient's emotions, values, or issues of authenticity, whose significance for a judgment of incompetence rests substantially on their relation to other factors. A contextual assessment of their impact on competence is therefore required, calling into question the value of the current standardizing approach.

Critics of the traditional model, clinicians in Switzerland, and even (in part) Grisso and Appelbaum agree that emotions, intuitions, and values are relevant in evaluating competence and should not be ignored. The crux of this lies in the assessment procedure. Instruments like the MacCAT-T fail to adequately operationalize the various impacts of emotions, intuitions, and values, so contributing to cognitive bias and provoking much criticism. Although it seems possible to rethink current standards in terms of their definition—as suggested for the *reasoning* standard—it is unlikely that standardized tools can ever be expected to fully capture the intricacies, the interrelatedness, and the contextual relevance of emotional and valuational factors. The only way to overcome cognitive bias is to rethink the methods used to assess relevant criteria.

As more than half of the surveyed clinicians believed that the therapeutic relationship has a substantial influence on competence judgments, it seems promising to place more emphasis on the relationship between patient and physician as an instrument of insight, for a number of reasons. First, within the patient-physician relationship as it evolves over time, a profound sense can be gained of the patient's personality and preferences, which better enables detection of any change or incoherence in their emotionality, values, or choices. Second, within the relationship between physician and patient, a co-constructive process of understanding and giving meaning to situations and experiences can evolve in ways that support and promote the patient's decision making, again allowing the physician to build a fuller sense of the patient and his concerns. Narrative approaches appear promising in this regard. Finally, judgment of emotional and valuational factors requires the evaluator to move beyond the evaluation of cognitive abilities in adopting the perspective of the patient

and empathizing deeply with them, which is a crucial tool in any assessment. As Aebi-Müller (2014, p. 13) claims: „[...] sie [die Motive des Patienten] müssen vielmehr annehmbar oder wenigstens einfühlbar sein. [...] Er [der Arzt] muss sich in das Weltbild des Patienten und in dessen Wertesystem einfühlen."

The variety of roles played by emotions and values, the variability of their expression, and the flexibility required in evaluating them create significant difficulties and objections to the formulation of clear-cut and operationalized criteria. Fortunately, this becomes less of a problem if incompetence is conceived as an ethical judgment that rests upon a comprehensive justification of medical paternalism. Once the relevant aspects align with an understanding of self-determination and are subject to critical reflection and appropriate weighting in arriving at a judgment that finds intersubjective acceptance, a lack of preformed criteria appears less problematic. From this point of view, the legal definition of competence, and of related subcategories (e.g., *Erkenntnisfähigkeit, Wertungsfähigkeit, Fähigkeit zur Willensbildung, Willenskraft*) that still leave room for interpretation, is actually adequate. Certainly, for clinical practice it is important to further specify these broad terms to help make sense of them in concrete cases. However, such specifications should take the form of possible detailed descriptions rather than of clear-cut and binding criteria.

8.3 Assessment

Clinicians in Switzerland feel more responsible than qualified to conduct evaluations of decision-making capacity, and express a need for guidelines, trainings, and tools for assessment. At present, competence evaluations are grounded on unstructured interviews conducted in the course of the regular consultation. Interestingly, however, a substantial proportion of clinicians would not use a (semi-)structured interview or standardized test procedure, probably reflecting the abovementioned objections to standardization. The requirement, then, is to reconcile the need for more guidance with criticisms of the standardized assessment of mental abilities. The utility of training and guidelines is beyond question; the problem lies with the tools. One promising solution might be to move from the standardized assessment of mental abilities by means of structured interiews and ratings to standardized documentation of the final competence judgment. By providing a documentation form instead of an interview form, several shortcomings of the current approach would be eliminated. First, the judgmental process would be foregrounded. The focus on mental abilities would be expanded by documenting additional information such as the consequences of a decision and, crucially, by documenting the integration of

information in explicating the arguments deeming a person incompetent. A different sort of quality managment would then become possible, addressing the adequacy of the balancing of moral values. Second, a documentation form would allow indication of the *kind* of information which is relevant to the assessment while leaving open *how* that information is to be collected. This would rid the encounter of any undesirable mechanistic elements, enabling an optimal and flexible response to the patient's needs and idiosyncracies.

The provision of a documentation form would be a first step toward overcoming the harsh sequential disjunction between the descriptive and the normative that risks an overemphasis on description. Early awareness and recognition of the normative dimension would be further promoted if moral intuitions were highlighted as the point of departure for every competence evaluation. The legal presumption of decision-making capacity and the related moral imperative to call a patient's competence into question only if there are substantial doubts *(*which is nothing else than a moral intuition*)* supports departure from such intuitions. The focus on moral intuitions can be a positive experience for evaluators; rather than having to conduct the evaluation from scratch and not knowing where to start, they can build on their own innate, intuitive knowledge. By concretizing moral intuitions meaningful general directions can be provided for more explicit exploration of patient characteristics and other influencing factors, such as characteristics of the situation or personal biases.

8.4 Supporting Physicians

In light of the above considerations, clinicians must learn to appreciate the inherent moral dimension of decision-making capacity, to become more aware of their moral intuitions by specifying and critically reflecting on them, to fully engage with the patient, to interpret relevant mental abilities in view of the entire person rather than merely assessing them in a rigid and isolated manner, to ethically deliberate, and to justify judgments of incompetence. As this places significant demands on medical practitioners, who must function in hectic and cash-strapped healthcare settings, questions arise about how best (and feasibly) to support them.

Competence evaluations are conducted in different contexts *(*e.g., hospitals, private practice), with different patient groups displaying diverse mental disturbances, and clinicians who are variously trained and specialized. Any proposition for training modules, guidelines, or tools must therefore take account of both feasibility and heterogeneity. This will require clear definition of the scope of application, including specification of the *kind*

of competence to be evaluated. The central theme of this thesis is a patient's competence to *consent to or refuse medical treatment*; other competence evaluations dealing, for instance, with making a will, managing one's finances, or assigning a durable power of attorney are quite distinct and must be separately treated.

A first step toward ensuring the efficiency of competence evaluations in clinical practice would be to triage cases. Clearly, the same thoroughness of evaluation and documentation will not be necessary for each patient, as the range between obvious competence and obvious incompetence is wide. The most challenging cases are those patients in between—the so-called "grey zone" cases, which require more thorough evaluation. For those who are obviously incompetent (e.g., patients who cannot express a choice or substantially lack understanding), brief documentation of deficient mental abilities should suffice. Whereas in "grey zone" cases, comprehensive documentation is both morally required and highly advisable for liability reasons where the patient is deemed *incompetent*. Against this, if the patient is eventually deemed *competent*, there is no comparable moral obligation to document the judgment in detail; a brief note in the patient record should suffice, signaling that the patient has been evaluated and deemed competent. However, depending on the case, comprehensive documentation may be advisable for liability reasons, especially in patients who are frequently deemed incompetent due to substantial and constant impairment of mental abilities, where an appeal is likely and a defense based on the legal presumption of competence is perhaps not a good prospect (see Figure 2).

Importantly, in line with the legal presumption, competence determinations should function by analogy with a *diagnosis of exclusion*. In the case of an incompetence judgment, that incompetence must be proven and paternalism must be justified; in the case of an competence judgment, incompetence must be excluded, arguing why paternalism is unjustified. As a logical consequence, if a "grey zone" patient is eventually deemed competent, it should suffice to argue why the mental functions of the patient *do not* legitimate an *incompetence* judgment. It is more efficient and easier to argue for incompetence than for competence—or to put it differently, *competence exists where there is no incompetence*. Consequently, it seems not necessary to provide detailed documentation of a competent patient's proper mental functioning; a brief note on the intactness of a particular function (e.g., understanding) would be sufficient. Thorough documentation of patient characteristics would be required only if these data support patient incompetence. It remains to be checked to what extent these recommendations align with legal practice regarding the burden of proof and courts' decisions in the case of an appeal. Yet,

considerations of this sort may help to minimize the time and effort needed to document judgments of competence or incompetence.

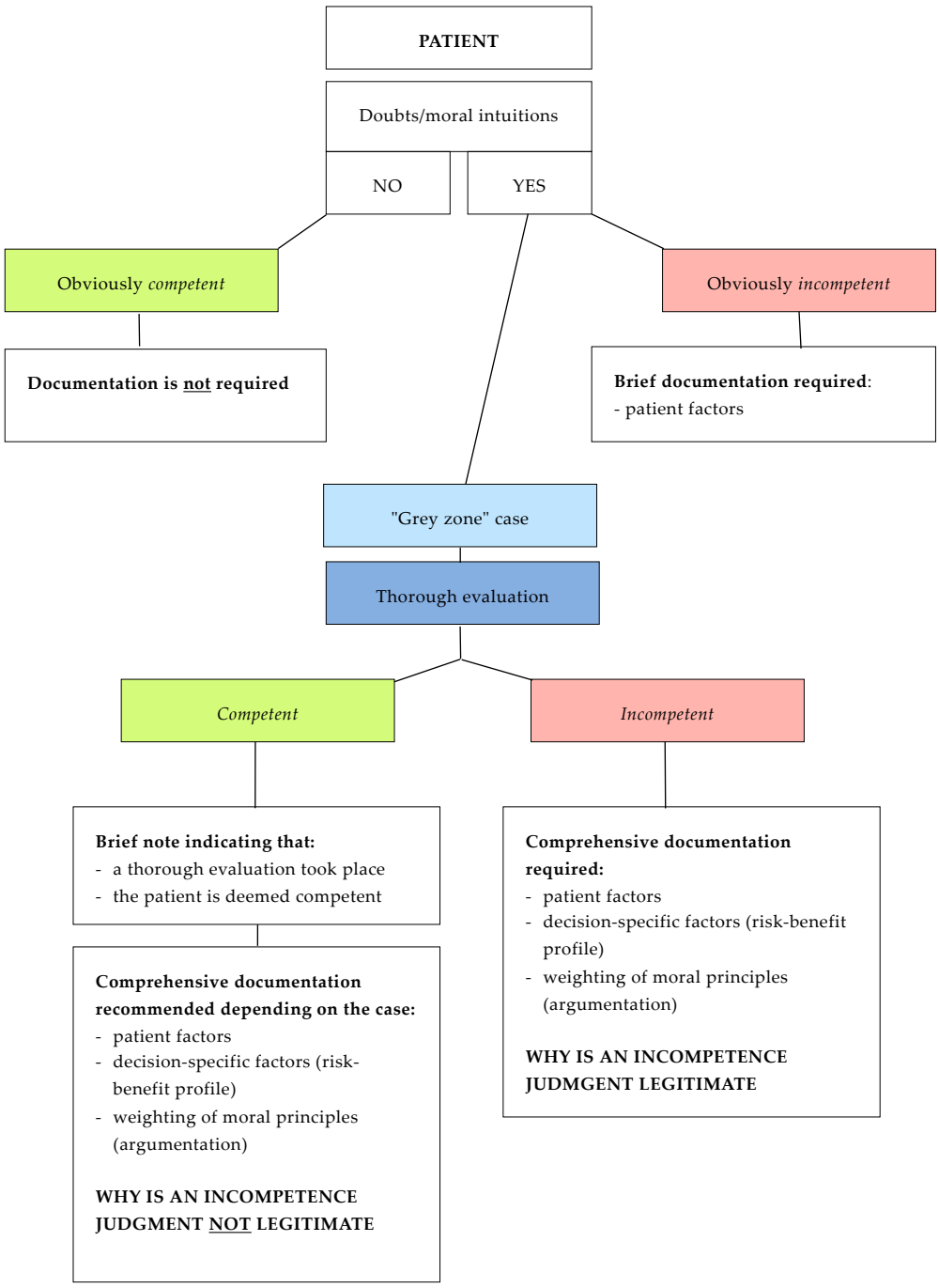

Figure 2. Suggestions for conditions regarding thorough evaluation and documentation.

With regard to the evaluation process in general, and particularly in respect of "grey zone" cases, the efficient, feasible, and adequate assessment of patient characteristics is probably best achieved by refraining from prescription of *how* the assessment should proceed, rather providing guidance solely about *what kind* of information is relevant. Interviews such as the MacCAT-T may be both helpful and feasible in certain instances, but in most cases, assigning a time slot of 30 minutes for discrete assessment is not realistic. Significantly, in that time only descriptive data can be gathered, and the complex judgment will remain outstanding. As the results of the survey suggest, assessment of patient factors normally takes place within the scope of a regular consultation. Presumably, relevant information is continuously collected and further probed during the encounter with the patient, or even over several encounters, within the scope of an unstructured dialog. In general, the *how* of the assessment appears very dependent on the context (e.g., outpatient or inpatient setting), and clinicians know how best they can efficiently acquire the information they require. Yet, free conversation with the patient should be encouraged in the interests of a genuine understanding of the patient rather than relying on standardized approaches to the measurement of single mental abilities.

So far, the following tools have been proposed: (1) a *documentation form* to facilitate quality management and concise review of relevant information; (2) a *glossary* that provides detailed and nuanced descriptions of relevant patient characteristics, including possible impacts of emotions and values and the role of authenticity, probably by means of *case examples*; (3) a *framework* that classifies the patient with regard to requirements for evaluation and documentation on grounds of both moral obligation and potential liability (see Figure 2), perhaps, accompanied by an additional brief outline of the *legal foundations* of decision-making capacity.

There is still no tool to support the judgmental process, the integration of information, or the balancing of moral principles. As Grisso and Appelbaum (1998a) argue, algorithms for these purposes will never be attainable. However, measures can be taken to facilitate and support this complex task. First of all, awareness of the moral dimension of competence evaluation is essential and must be heightened. Clinicians should have a proper grasp of what the normative component of decision-making capacity really entails and should conceive of it as an ethical judgment. This will probably demand a profound reconfiguration of their current conception of competence. However, I am convinced that once this rethinking took place, competence evaluations would probably become much clearer (though hardly easier) with the identification and naming of difficulties arising

mainly from the balancing of moral values. Moreover, once the moral dimension of decision-making capacity is acknowledged, making sense of moral intuitions (and deploying them) can become a crucial tool, particularly in difficult cases, reframing the evaluation process to better integrate normative and descriptive considerations. Awareness of this sort is probably best achieved through training and education. Additionally, it may be helpful to provide a synopsis of the most important elements of decision-making capacity in the form of *general principles*, along with an *illustration of the evaluation process* (see Figure 3).

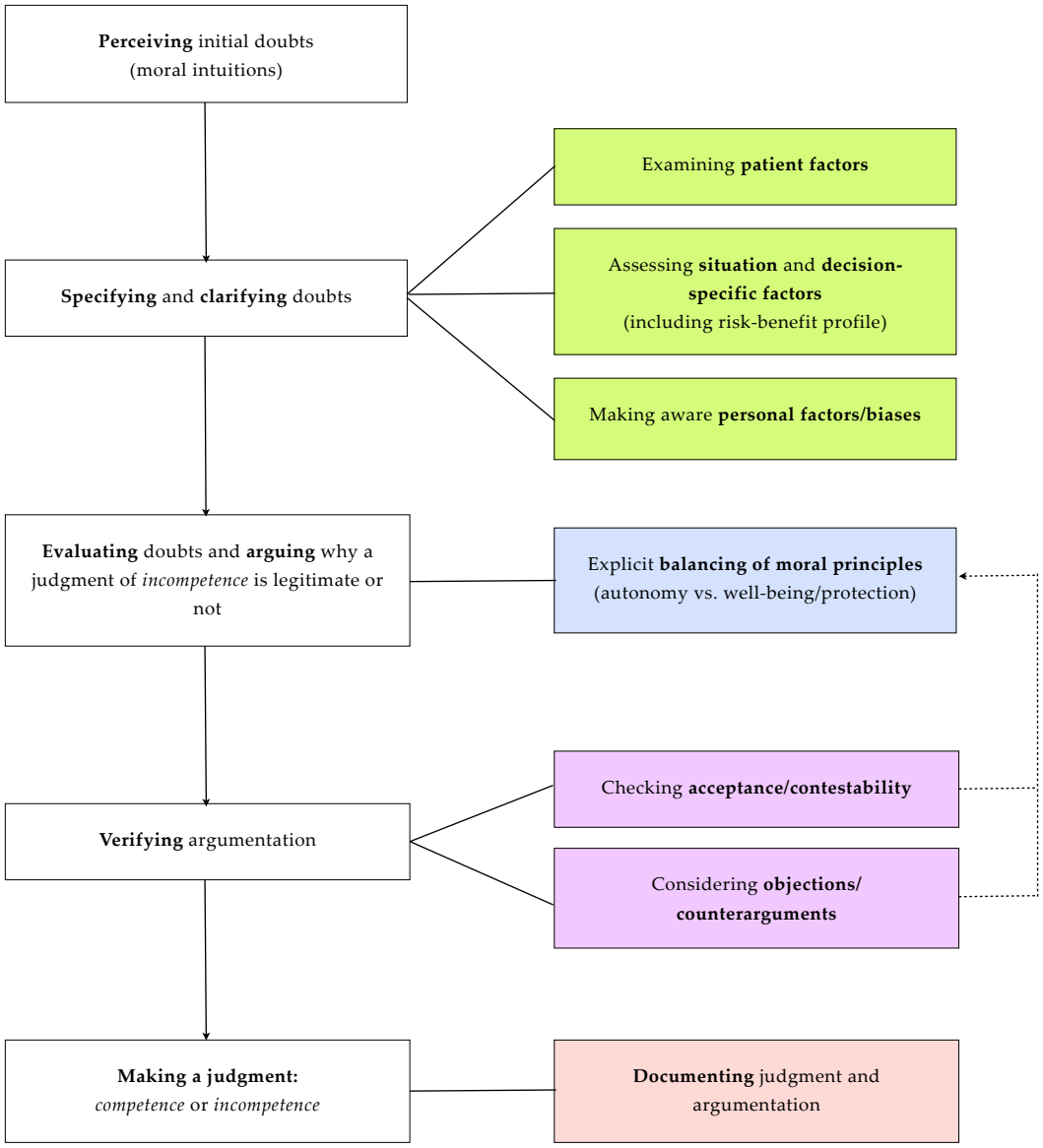

Figure 3. Evaluation process.

Second, although clinical cases are highly idiosyncratic and are never completely congruent with other cases and circumstances, it may be possible to facilitate and promote ethical deliberation, particularly in difficult cases by drawing analogies between cases. A collection of cases with detailed descriptions of how competence or incompetence judgments have been reached would be helpful, not only in finding solutions in particular instances but also for education purposes, sharpening practitioners' moral sensitivity and delivering a sense of what it means to balance moral values, and what forms this can take.

Third, in challenging cases, ethical deliberation may benefit from an exchange with others whose views support or challenge one's own appraisal. A judgment based on discourse will be more solidly grounded, ensuring quality and giving the responsible physician greater confidence. Vessels for exchange are important structural preconditions that can take different forms according to context.

In general, moral and interpersonal sensitivity, the capacity for critical self-reflection, articulateness, and benevolence are essential skills and virtues in the evaluation of decision-making capacity that rest essentially on the individual talents, education, and professional socialization of clinicians, as well as on the climate in which they practice. In short, tools and guidelines are useful, but they cannot achieve these goals alone.

8.5 Future Research

Research on decision-making capacity and good evaluation practice is certainly not yet exhausted. The present thesis has identified a variety of promising directions for future empirical investigations and theoretical analyses. First, the above proposals to support and enhance competence evaluations in clinical practice will require empirical evaluation of their feasibility, utility, and ultimately of their effectiveness.

Second, empirical research to date has focused almost exclusively on patients and their decision-making capacities while evaluating clinicians were examined mainly with regard to their knowledge, attitudes, or general aspects of assessment, by means of quantitative surveys. There is little detailed qualitative investigation of the judgmental process, and this would appear to be a very promising direction for further research. Such studies would provide more and deeper insights into the weighing of particular kinds of information about the patient or the situation, and how physicians' own values come into play in this balancing process. On this basis, detailed ethical analyses of the fine line between justified and unjustified paternalism could also be conducted. Moreover, the collected data would enable fine-grained case analyses, promoting a fuller understanding of relevant patient

factors with particular regard to substantive impacts of patients' values and emotions or issues of authenticity. From this perspective, a documentation form may serve an additional purpose as an important source of data for qualitative analyses.

Third, there is a need to further elaborate and develop appropriate and innovative methods for the assessment of patient factors and for the integration of information into a final judgment. The potential of narrative approaches, relational aspects, and moral intuitions, as well as the utility of analogies in moral reasoning, have been established. In general, assessing and learning from the methods used in clinical ethics consultations seems likely to promote good practice in competence evaluations.

Fourth, from a theoretical perspective, a range of intriguing questions are in need of further analysis. I will outline just two of the possible strands for future investigation. First, it appears crucial to reassess the concept of decision-making capacity in the context of shared decision-making. According to existing legal provisions, (in)competence establishes a clear demarcation between autonomy and heteronomy that blurs or dissolves from the perspective of shared decision-making. Additionally, an increased emphasis on decision-making support may eclipse discrete competence judgments. In consequence, the role and significance of competence evaluations may change to be perceived differently by the law and by medical practice, perhaps giving rise to untenable discrepancies between the two.

Second, further reflection on the relation between competence and psychiatric disorders seems worthwhile. As has been demonstrated, judgments regarding substantive factors and authenticity rely heavily on psychiatric diagnoses. Mere awareness of such a diagnosis and associated representations and images can frame the judgment, lending the situation an entirely different meaning. It is crucial to understand these effects, as they provide a sense of the broader normative frame underpinning competence judgments. Moreover, the extent to which people with a psychiatric diagnosis are required to be more "normal" than people without a psychiatric diagnosis in order to be deemed competent remains to be analyzed. While the "healthy" eccentric is explicitly granted the right to self-determination, the eccentric with a psychopathology seems likely to experience a harder time, and the potential for discrimination in competence evaluations against persons with a psychiatric diagnosis certainly requires attention.

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Appendices

Survey Questionnaire - German

Universität Zürich[UZH]

Institut für Biomedizinische Ethik

Fragebogen zur ärztlichen Beurteilung von Urteilsfähigkeit in der Schweiz

Dr. phil. Manuel Trachsel
Helena Hermann, M.Sc.
Prof. Dr. med. Dr. phil. Nikola Biller-Andorno

Umfrage im Rahmen des Forschungsprojekts

Decision-making incapacity at the end of life and its assessment in Switzerland

Lebensende
Nationales Forschungsprogramm NFP 67

FNSNF
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In Kooperation mit der
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Universität Zürich[UZH]

Sehr geehrte Ärztin, sehr geehrter Arzt

Bereits jetzt möchten wir Ihnen danken, dass Sie an dieser Studie teilnehmen.

Auf den folgenden Seiten finden Sie Fragen zum Themenbereich „Ärztliche Beurteilung von Urteilsfähigkeit", zu deren Beantwortung Sie circa 15 Minuten benötigen werden.

Die Daten werden absolut vertraulich behandelt und nur anonymisiert weiterverwendet.

Besten Dank!

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Zu Beginn möchten wir Sie bitten, folgende Fragen zu Ihrer Person und zu Ihrem Beruf zu beantworten.

Alter in Jahren: ☐

Geschlecht:
- O weiblich
- O männlich

Aktuelles Arbeitsfeld:
- O Hausarztpraxis
- O Spezialarztpraxis
- O Spital
- O sonstiges Arbeitsfeld

Beschäftigungsgrad:
- O Teilzeit
- O Vollzeit

Sind Sie aktuell in der Patientenversorgung tätig?
- O ja
- O nein

Ärztliche Berufserfahrung: ☐

(Bitte in Anzahl Jahren angeben)

Facharzttitel:

- O Allergische und immunologische Krankheiten (Allergologie und klinische Immunologie)
- O Allgemeine Innere Medizin
- O Allgemeinmedizin
- O Anästhesiologie
- O Arbeitsmedizin
- O Augenkrankheiten (Ophthalmologie)
- O Blasen-, Nieren- und Prostatakrankheiten (Urologie)
- O Blutkrankheiten (Hämatologie)
- O Chirurgie
- O Frauenkrankheiten und Geburtshilfe (Gynäkologie und Geburtshilfe
- O Gefässkrankheiten (Angiologie)
- O Gehirn- und Nervenchirurgie (Neurochirurgie)

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- o Handchirurgie
- o Haut- und Geschlechtskrankheiten (Dermatologie und Venerologie)
- o Herz- und thorakale Gefässchirurgie
- o Herzkrankheiten (Kardiologie)
- o Hormonkrankheiten und Diabetes (Endokrinologie-Diabetologie)
- o Infektionskrankheiten (Infektiologie)
- o Innere Medizin
- o Intensivmedizin
- o Kinder- und Jugendmedizin
- o Kinder- und Jugendpsychiatrie und -psychotherapie
- o Kinderchirurgie
- o Klinische Pharmakologie und Toxikologie
- o Lungenkrankheiten (Pneumologie)
- o Magen- und Darmkrankheiten (Gastroenterologie)
- o Medizinische Genetik
- o Mund-, Kiefer- und Gesichtschirurgie
- o Nervenkrankheiten (Neurologie)
- o Neuropathologie
- o Nierenkrankheiten (Nephrologie)
- o Nuklearmedizin
- o Ohren-, Nasen- und Halskrankheiten
- o Orthopädische Chirurgie
- o Pathologie
- o Pharmazeutische Medizin
- o Physikalische Medizin und Rehabilitation
- o Plastisch-Rekonstruktive und Aesthetische Chirurgie
- o Praktischer Arzt/ Praktische Ärztin
- o Prävention und Gesundheitswesen
- o Psychiatrie und Psychotherapie
- o Radio-Onkologie/ Strahlentherapie
- o Radiologie
- o Rechtsmedizin
- o Rheumaerkrankungen (Rheumatologie)
- o Tropen- und Reisemedizin
- o Tumorerkrankungen (Medizinische Onkologie)

Andere:

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ÄrztInnen in unterschiedlichen Fachbereichen begegnen immer wieder Situationen, in denen die Urteilsfähigkeit von Patienten fraglich ist und beurteilt werden muss.

Urteilsfähigkeit ist z.B. in folgenden Situationen wichtig:

- Wenn die Zustimmung zu einer bestimmten Abklärung oder Therapie eingeholt werden muss.
- Wenn PatientInnen eine Patientenverfügung verfassen.
- Wenn PatientInnen einen ärztlich assistierten Suizid wünschen.

Frage 1:

Fühlen Sie sich in Ihrer ärztlichen Tätigkeit **zuständig,** Urteilsfähigkeit zu beurteilen?

- O nicht dafür zuständig
- O eher nicht dafür zuständig
- O eher dafür zuständig
- O sicher dafür zuständig

Frage 2:

Fühlen Sie sich **genügend qualifiziert**, um Urteilsfähigkeit ärztlich zu beurteilen?

- O nicht genügend qualifiziert
- O eher nicht genügend qualifiziert
- O eher genügend qualifiziert
- O sicher genügend qualifiziert

Frage 3:

Ist Urteilsfähigkeit für Sie eher ein **Alles-oder-Nichts-Konzept** (jemand ist für eine bestimmte Entscheidung entweder urteilsfähig oder nicht urteilsfähig) oder ist Urteilsfähigkeit für Sie eher ein **graduelles Konzept** mit feineren Abstufungen (jemand ist für eine bestimmte Entscheidung mehr oder weniger urteilsfähig)?

- O Alles-oder-Nichts-Konzept
- O Graduelles Konzept
- O Ich bin unschlüssig

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Frage 4:

Für wie relevant erachten Sie die folgenden **mentalen Fähigkeiten** als Kriterien für Urteilsfähigkeit?

	gar nicht relevant	eher nicht relevant	eher relevant	sehr relevant
Informationen in Bezug auf die zu fällende Entscheidung verstehen.	O	O	O	O
Die Bedeutung der vermittelten Informationen über die Krankheit und deren mögliche Behandlung für die eigene Person ermessen (Krankheits- und Behandlungseinsicht).	O	O	O	O
Die Situation und die Konsequenzen abwägen, die sich aus den alternativen Möglichkeiten ergeben.	O	O	O	O
Die erhaltene Information vor dem Hintergrund der eigenen Werte und Einstellungen gewichten.	O	O	O	O
Sich auf die eigene Biografie, Erfahrungen und intuitives Wissen beziehen.	O	O	O	O
Sich emotional am Entscheidungsprozess beteiligen.	O	O	O	O
Die eigene Wahl äussern.	O	O	O	O

Frage 5:

Beurteilen Sie die Urteilsfähigkeit einer PatientIn jeweils in Abhängigkeit davon, **wie schwerwiegend die (potentiellen) Folgen** einer medizinischen Entscheidung sind? Setzen Sie zum Beispiel bei schwerwiegenderen Folgen höhere **Anforderungen an die mentalen Fähigkeiten**?

- O Die Schwere der Folgen ist für meine Beurteilung **gar nicht relevant.**
- O Die Schwere der Folgen ist für meine Beurteilung **eher nicht relevant.**
- O Die Schwere der Folgen ist für meine Beurteilung **eher relevant.**
- O Die Schwere der Folgen ist für meine Beurteilung **sehr relevant.**

- O Diese Frage kann ich nicht beantworten, da ich Urteilsfähigkeit noch nie selbst beurteilt habe.

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Frage 6:

Stellen Sie sich bitte folgende Situation vor:

Ein Patient ist mit der Entscheidung konfrontiert, seine Krebserkrankung durch eine Chemotherapie behandeln zu lassen oder nicht. Die Wahrscheinlichkeit, dass durch die Chemotherapie das Tumorwachstum nachhaltig gestoppt wird und kein Rezidiv auftritt, liegt bei 70%. Das Ausbleiben einer entsprechenden Behandlung würde hingegen mit hoher Wahrscheinlichkeit innerhalb weniger Monate zum Tod führen. Andere sinnvolle Behandlungsmöglichkeiten existieren in diesem Fall nicht. Die Urteilsfähigkeit des Patienten ist fraglich und verlangt nach einer genaueren Prüfung.

In welchem Fall setzen Sie **höhere Anforderungen an die mentalen Fähigkeiten** zur Beurteilung von Urteilsfähigkeit?

- O Der Patient entscheidet sich für die Chemotherapie.
- O Der Patient entscheidet sich gegen die Chemotherapie (Behandlungsverzicht).
- O Ich setze in beiden Fällen gleich hohe Anforderungen an die mentalen Fähigkeiten.

Frage 7:

Der Patient aus der Fallvignette der letzten Frage (Frage 6) entscheidet sich gegen eine Chemotherapie (Behandlungsverzicht). Stattdessen wünscht er einen **assistierten Suizid**.

Sie werden konsultiert, um die Urteilsfähigkeit des Patienten zu beurteilen.
Welche Anforderungen müssen erfüllt sein, damit Sie den Patienten für urteilsfähig erklären?

(mehrere Antworten möglich)

- O Gleich hohe Anforderungen an die mentalen Fähigkeiten wie beim Behandlungsverzicht.
- O Höhere Anforderungen an die mentalen Fähigkeiten als beim Behandlungsverzicht.
- O Ich muss persönlich davon überzeugt sein, dass ein assistierter Suizid die beste Option ist, die dem Patienten zur Verfügung steht.

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Frage 8:

Stellen Sie sich bitte folgende Situation vor:

Eine demente Patientin leidet an einer Niereninsuffizienz, weswegen eine Umstellung der medikamentösen Behandlung nötig wird (Intervention 1). Zu diesem Zeitpunkt fehlt der Patientin jedoch die Urteilsfähigkeit hinsichtlich der Medikamentenumstellung und der Arzt verordnet diese in Absprache mit den vertretungsberechtigten Personen. Bei derselben Konsultation muss ein operativer Eingriff aufgrund eines bösartigen Hauttumors an der Nase besprochen werden (Intervention 2).

Wie würden Sie beim Einholen der Zustimmung für Intervention 2 vorgehen?

- O Da die Urteils**un**fähigkeit bereits im Zusammenhang mit Intervention 1 erfasst wurde, spreche ich mich bezüglich der Durchführung von Intervention 2 ebenfalls mit den vertretungsberechtigten Personen ab.
- O Da es sich um zwei unterschiedliche Interventionen handelt, beurteile ich die Urteilsfähigkeit der Patientin noch einmal separat für Intervention 2 und entscheide erst dann, ob ich für die Durchführung der Behandlung die Zustimmung der vertretungsberechtigten Personen einhole.

Frage 9:

Wie stark fliessen die folgenden **Faktoren** ein, wenn Sie die Urteilsfähigkeit von PatientInnen beurteilen?

- O Diese Frage kann ich nicht beantworten, da ich Urteilsfähigkeit noch nie selbst beurteilt habe.

	gar nicht	mässig	ziemlich	sehr
Die therapeutische Beziehung	O	O	O	O
Der psychopathologische Befund	O	O	O	O
Der somatische Befund	O	O	O	O
Der medizinische Kontext (z.B. Dringlichkeit der Behandlung)	O	O	O	O
Meine eigenen Werthaltungen	O	O	O	O
Der soziale Kontext (z.B. Ausmass der sozialen Unterstützung von PatientInnen)	O	O	O	O
Die Komplexität der Behandlungsoptionen (z.B. Ablauf der Behandlung, bestehende Vor- und Nachteile)	O	O	O	O
Informationen / Aussagen von vertrauten Personen der PatientInnen	O	O	O	O

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Frage 10:

Wie häufig beurteilen Sie bei folgenden Patienten die Urteilsfähigkeit genauer?

	nie	selten	oft	immer	nicht beurteilbar (ich behandle keine solchen Patienten)
Demenz vom Alzheimer-Typ	O	O	O	O	O
Milde kognitive Störung (mild cognitive impairment)	O	O	O	O	O
Unipolare Depression	O	O	O	O	O
PatientInnen in stationärer Behandlung auf der inneren Medizin	O	O	O	O	O
Schizophrenie	O	O	O	O	O
Gliom	O	O	O	O	O
Gesunde ältere Personen	O	O	O	O	O
Morbus Parkinson	O	O	O	O	O
PatientInnen am Lebensende	O	O	O	O	O
Lernbehinderung	O	O	O	O	O

Bitte machen Sie eine Rangliste der **drei** am häufigsten mit Urteils**un**fähigkeit assoziierten Erkrankungen (unabhängig von Ihrem Arbeitsfeld):

1)

2)

3)

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Frage 11:

Machen Sie die folgenden **Verhaltensweisen** von PatientInnen auf die Frage nach der Urteilsfähigkeit **aufmerksam**?

	nie	in den seltensten Fällen	in den meisten Fällen	immer
Ein/e PatientIn ist nicht einverstanden mit einer ärztlich verordneten Diagnostik/Therapie.	O	O	O	O
Ein/e PatientIn fällt schwer nachvollziehbare Entscheidungen (z.B. Wunsch nach assistiertem Suizid bei behandelbarem Leiden).	O	O	O	O
Ein/e PatientIn gibt jede Entscheidungen hinsichtlich der Behandlung an den/die ÄrztIn oder eine andere Person ab, da er/sie es sich selbst nicht zutraut, richtig zu entscheiden.	O	O	O	O
Ein/e PatientIn gefährdet sich selbst oder andere unmittelbar (z.B. Suizidalität oder körperliche Bedrohung anderer).	O	O	O	O
Ein/e PatientIn ist verzweifelt und stimmt allen Behandlungsvorschlägen sofort und unkritisch zu.	O	O	O	O
Ein/e PatientIn äussert, dass ihr/ihm die Entscheidung egal ist.	O	O	O	O
Ein/e PatientIn wechselt wiederholt die Meinung hinsichtlich einer bestimmten Behandlungsoption.	O	O	O	O

Frage 12:

Wie häufig erleben Sie es in Ihrem Arbeitsalltag, dass die Urteilsfähigkeit von PatientInnen **fraglich** ist?

- O nie
- O selten
- O oft
- O immer

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Frage 13:

Wenn die Urteilsfähigkeit von PatientInnen fraglich ist, auf **welche Art** überprüfen Sie diese?

(Bitte geben Sie bei jeder Aussage eine Antwort an)

	nie	selten	oft	immer
Ich beurteile die Urteilsfähigkeit im Rahmen der üblichen Konsultation (**implizite Beurteilung).**	O	O	O	O
Ich räume der Erfassung von Urteilsfähigkeit separaten Platz während der Konsultation ein (**explizite Beurteilung).**	O	O	O	O
Ich konsultiere **spezialisierte KollegInnen.**	O	O	O	O

Falls Sie die Urteilsfähigkeit **nie explizit** beurteilen, überspringen Sie bitte Frage 14 – 16 und gehen Sie direkt zu **Frage 17**.

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Frage 14:

Wenn Sie die Urteilsfähigkeit **explizit** beurteilen, welche der folgenden Methoden wenden Sie an?

(mehrere Antworten möglich)

O Freies Interview mit eigenen situationsabhängigen Fragen

O Halbstandardisiertes Interview mit teilweise vorgegebenen Fragen

Falls ja, Name und Quelle des Interviews:

O Standardisiertes Interview mit genau vorgegebenen Fragen

Falls ja, Name und Quelle des Interviews:

O Fragebogen oder schriftlicher Test

Falls ja, Name und Quelle des Instruments:

O Nicht-schriftliches Testverfahren (z.B. Bilder, Karten, mündlicher Test)

Falls ja, Name und Quelle des Instruments:

O Keine der genannten Methoden

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Frage 15:

Wenn Sie die Urteilsfähigkeit **explizit** beurteilen, **kündigen Sie den PatientInnen an**, dass es nun bei den nächsten Fragen darum geht, die Urteilsfähigkeit zu erfassen?

- O nie
- O selten
- O oft
- O immer

Frage 16:

Falls Sie Frage 15 mit „selten", „oft" oder „immer" beantwortet haben:

Weshalb kündigen Sie die Erfassung der Urteilsfähigkeit an?

Wie kündigen Sie die Erfassung der Urteilsfähigkeit an?

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Frage 17:

Bitte denken Sie an die schwierigsten Fälle, die Sie im Zusammenhang mit der Beurteilung von Urteilsfähigkeit erlebt haben.

Welche Aspekte haben Ihnen die Beurteilung **am meisten erschwert**?

(Kreuzen Sie bis max. 4 Antwortalternativen an)

- O Die Berücksichtigung von Risiko-Nutzen-Abwägungen in der abschliessenden Beurteilung
- O Fälle mit grenzwertiger Urteilsfähigkeit („Grauzonen-Fälle"), die weder eindeutig urteilsfähig noch eindeutig urteilsunfähig waren
- O Sehr komplexe ethische Situationen
- O Uneinigkeiten zwischen den behandelnden Ärzten oder mit der Pflege
- O Patientenfaktoren (z.B. mangelnde Kooperationsbereitschaft)
- O Eine chaotische oder konfliktreiche familiäre Situation
- O Unklarheit des rechtlichen Kontexts
- O Keiner der genannten Aspekte

- O Diese Frage kann ich nicht beantworten, da ich Urteilsfähigkeit noch nie selbst beurteilt habe.

Frage 18:

Wie häufig treten die unter Frage 17 beschriebenen Schwierigkeiten auf, wenn Sie eine fragliche Urteilsfähigkeit genauer abklären?

- O nie
- O selten
- O oft
- O immer

- O Diese Frage kann ich nicht beantworten, da ich Urteilsfähigkeit noch nie selbst beurteilt habe.

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Frage 19:

Welche der folgenden **Interventionen/Strategien**, um die Urteilsfähigkeit Ihrer PatientInnen zu **verbessern,** können Sie in Ihrem klinischen Alltag umsetzen?

Ich verschiebe die Beurteilung der Urteilsfähigkeit auf einen späteren Zeitpunkt, wenn der Patient gerade in schlechter Verfassung erscheint.

- O Dies finde ich wichtig, kann ich aber nicht umsetzen.
- O Dies finde ich wichtig, kann ich aber nur eingeschränkt umsetzen.
- O Dies kann ich in den meisten Fällen umsetzen.
- O Dies finde ich keine relevante Intervention/Strategie.

Ich passe die Art und Weise, wie ich die Informationen präsentiere, an die PatientInnen an (z.B. durch zusätzliche Informationen in schriftlicher Form, Veranschaulichung mit Diagrammen und Illustrationen, Hinzuziehen von Übersetzern).

- O Dies finde ich wichtig, kann ich aber nicht umsetzen.
- O Dies finde ich wichtig, kann ich aber nur eingeschränkt umsetzen.
- O Dies kann ich in den meisten Fällen umsetzen.
- O Dies finde ich keine relevante Intervention/Strategie.

Ich verändere die Einstellung von Medikamenten, welche die mentalen Fähigkeiten beeinflussen können.

- O Dies finde ich wichtig, kann ich aber nicht umsetzen.
- O Dies finde ich wichtig, kann ich aber nur eingeschränkt umsetzen.
- O Dies kann ich in den meisten Fällen umsetzen.
- O Dies finde ich keine relevante Intervention/Strategie.

Ich ermutige die PatientInnen, sich mit vertrauten Personen bezüglich der bevorstehenden Entscheidung auszutauschen.

- O Dies finde ich wichtig, kann ich aber nicht umsetzen.
- O Dies finde ich wichtig, kann ich aber nur eingeschränkt umsetzen.
- O Dies kann ich in den meisten Fällen umsetzen.
- O Dies finde ich keine relevante Intervention/Strategie.

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Ich gebe den PatientInnen die Möglichkeit, sich von einer vertrauten Person begleiten zu lassen.

- O Dies finde ich wichtig, kann ich aber nicht umsetzen.
- O Dies finde ich wichtig, kann ich aber nur eingeschränkt umsetzen.
- O Dies kann ich in den meisten Fällen umsetzen.
- O Dies finde ich keine relevante Intervention/Strategie.

Ich sorge speziell dafür, dass das Gespräch in einer angenehmen und ruhigen Atmosphäre stattfindet.

- O Dies finde ich wichtig, kann ich aber nicht umsetzen.
- O Dies finde ich wichtig, kann ich aber nur eingeschränkt umsetzen.
- O Dies kann ich in den meisten Fällen umsetzen.
- O Dies finde ich keine relevante Intervention/Strategie.

Ich berücksichtige und thematisiere psychische Aspekte, wie Ängste und vermeidende Tendenzen der PatientInnen, oder führe hierzu kurze psychotherapeutische Interventionen durch.

- O Dies finde ich wichtig, kann ich aber nicht umsetzen.
- O Dies finde ich wichtig, kann ich aber nur eingeschränkt umsetzen.
- O Dies kann ich in den meisten Fällen umsetzen.
- O Dies finde ich keine relevante Intervention/Strategie.

Frage 20:

Kennen Sie die im Folgenden genannten Beurteilungsinstrumente und wenden Sie diese an?

Mac Arthur Competence Assessment Tool (MacCAT)

- O Von diesem Instrument habe ich noch nie gehört.
- O Von diesem Instrument habe ich schon gehört, kenne es jedoch nicht genauer.
- O Ich kenne das Instrument, habe es jedoch noch nie angewendet.
- O Ich habe das Instrument bereits angewendet, verwende es jedoch nicht mehr, da ich es nicht nützlich finde.
- O Ich wende das Instrument regelmässig an.

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Aid to Capacity Evaluation (ACE)

- O Von diesem Instrument habe ich noch nie gehört.
- O Von diesem Instrument habe ich schon gehört, kenne es jedoch nicht genauer.
- O Ich kenne das Instrument, habe es jedoch noch nie angewendet.
- O Ich habe das Instrument bereits angewendet, verwende es jedoch nicht mehr, da ich es nicht nützlich finde.
- O Ich wende das Instrument regelmässig an.

Silberfeld's Competence Tool

- O Von diesem Instrument habe ich noch nie gehört.
- O Von diesem Instrument habe ich schon gehört, kenne es jedoch nicht genauer.
- O Ich kenne das Instrument, habe es jedoch noch nie angewendet.
- O Ich habe das Instrument bereits angewendet, verwende es jedoch nicht mehr, da ich es nicht nützlich finde.
- O Ich wende das Instrument regelmässig an.

Hopkins Competency Assessment Tool (HCAT)

- O Von diesem Instrument habe ich noch nie gehört.
- O Von diesem Instrument habe ich schon gehört, kenne es jedoch nicht genauer.
- O Ich kenne das Instrument, habe es jedoch noch nie angewendet.
- O Ich habe das Instrument bereits angewendet, verwende es jedoch nicht mehr, da ich es nicht nützlich finde.
- O Ich wende das Instrument regelmässig an.

Anderes:

- O Ich habe das Instrument bereits angewendet, verwende es jedoch nicht mehr, da ich es nicht nützlich finde.
- O Ich wende das Instrument regelmässig an.

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Frage 21:

Welche Art von zusätzlichen Hilfsmitteln zur Beurteilung der Urteilsfähigkeit würden Sie in Ihrer klinischen Praxis wahrscheinlich anwenden?

(mehrere Antworten möglich)

- O Halbstandardisiertes Interview mit teilweise vorgegebenen Fragen
- O Standardisiertes Interview mit genau vorgegebenen Fragen
- O Fragebogen oder schriftlicher Test
- O Nicht-schriftliches Testverfahren
- O Keines der genannten Hilfsmittel

Frage 22:

Fänden Sie es hilfreich, wenn es für die Beurteilung von Urteilsfähigkeit **offizielle Richtlinien** (z.B. von der SAMW) gäbe?

- O Ich fände dies überhaupt nicht hilfreich.
- O Ich fände dies eher nicht hilfreich.
- O Ich fände dies eher hilfreich.
- O Ich fände dies sehr hilfreich.

Frage 23:

Wie sinnvoll fänden Sie es, wenn die systematische Beurteilung von Urteilsfähigkeit ausführlicher **in der ärztlichen Aus-, Weiter- und Fortbildung** behandelt würde, als Sie dies persönlich erfahren haben bzw. erfahren?

- O Ich fände dies überhaupt nicht sinnvoll.
- O Ich fände dies eher nicht sinnvoll.
- O Ich fände dies eher sinnvoll.
- O Ich fände dies sehr sinnvoll.

Besten Dank!

Survey Questionnaire - French

Universität Zürich[UZH]

Institut d'éthique biomédicale

Questionnaire concernant l'évaluation médicale de la capacité de discernement en Suisse

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Helena Hermann, M.Sc.
Prof. Dr. med. Dr. phil. Nikola Biller-Andorno

Enquête dans le cadre du projet de recherche

Decision-making incapacity at the end of life and its assessment in Switzerland

Fin de vie
Programme national de recherche PNR 67

FNSNF
Fonds national suisse
Schweizerischer Nationalfonds
Fondo nazionale svizzero
Swiss National Science Foundation

En coopération avec
l'Académie Suisse des Sciences Médicales ASSM

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Universität Zürich[UZH]

Madame, Monsieur

Nous vous remercions d'ores et déjà de participer à cette étude.

Les réponses au questionnaire ci-après concernant le thème de l'évaluation médicale de la capacité de discernement vous demanderont environ 15 minutes.

Les données ainsi recueillies resteront totalement confidentielles et ne seront transmises que sous forme anonymisée.

Merci beaucoup!

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Pour commencer, nous vous prions de répondre aux questions suivantes concernant votre personne et votre profession.

Âge: ☐

Sexe:
- O féminin
- O masculin

Domaine d'activité actuel:
- O cabinet de médecin de famille
- O cabinet de médecin spécialiste
- O hôpital
- O autre

Taux d'occupation:
- O temps partiel
- O plein temps

Actuellement, prenez-vous en charge des patients ?
- O oui
- O non

Expérience médicale: ☐

(prière d'indiquer en nombre d'années)

Titres de spécialiste:

- O Allergologie et immunologie clinique
- O Anesthésiologie
- O Angiologie
- O Cardiologie
- O Chirurgie
- O Chirurgie cardiaque et vasculaire thoracique
- O Chirurgie de la main
- O Chirurgie orale et maxillo-faciale
- O Chirurgie orthopédique
- O Chirurgie pédiatrique
- O Chirurgie plastique, reconstructive et esthétique
- O Dermatologie et vénéréologie
- O Endocrinologie - diabétologie

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- o Gastroentérologie
- o Génétique médicale
- o Gynécologie et obstétrique
- o Hématologie
- o Maladies des reins (Néphrologie)
- o Maladies infectieuses (Infectiologie)
- o Médecin praticien
- o Médecine du travail
- o Médecine générale
- o Médecine intensive
- o Médecine interne
- o Médecine interne générale
- o Médecine légale
- o Médecine nucléaire
- o Médecine pharmaceutique
- o Médecine physique et réadaptation
- o Médecine tropicale et médecine des voyages
- o Neurochirurgie
- o Neurologie
- o Neuropathologie
- o Oncologie médicale
- o Ophtalmologie
- o Oto-rhino-laryngologie
- o Pathologie
- o Pédiatrie
- o Pharmacologie et toxicologie cliniques
- o Pneumologie
- o Prévention et santé publique
- o Psychiatrie et psychothérapie
- o Psychiatrie et psychothérapie d'enfants et d'adolescents
- o Radio-oncologie/ radiothérapie
- o Radiologie
- o Rhumatologie
- o Urologie

Autres:

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Les médecins et spécialistes sont régulièrement confrontés à des situations dans lesquelles la capacité de discernement des patients est sujette à caution et doit être évaluée.

La capacité de discernement est importante dans les situations suivantes, par exemple :

- Lorsque le patient doit consentir à des examens ou à une thérapie.
- Lorsque le patient a rédigé des directives anticipées.
- Lorsque le patient demande une assistance médicale au suicide.

Question 1:

Pensez-vous que l'évaluation de la capacité de discernement d'un patient fait partie de votre activité médicale?

- O non
- O plutôt non
- O plutôt oui
- O certainement

Question 2:

Vous sentez-vous **suffisamment qualifié(e)** pour évaluer la capacité de discernement d'un point de vue médical?

- O pas assez qualifié(e)
- O plutôt pas assez qualifié(e)
- O plutôt assez qualifié(e)
- O certainement assez qualifié(e)

Question 3:

Considérez-vous la capacité de discernement comme un **concept du tout-ou-rien** (une personne est soit capable, soit incapable de discernement pour une décision déterminée) ou plutôt comme un **concept graduel** avec des gradations plus subtiles (une personne est plus ou moins capable de discernement pour une décision déterminée)?

- O Concept du tout-ou-rien
- O Concept graduel
- O Je suis indécis

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Question 4:

Quel degré d'importance accordez-vous aux **capacités mentales** suivantes en tant que critères pour l'évaluation de la capacité de discernement?

	aucune importance	plutôt sans importance	plutôt important	très important
Comprendre les informations relatives à la décision à prendre.	O	O	O	O
Mesurer ce qu'impliquent pour soi-même les informations transmises sur la maladie et les traitements possibles (prise de conscience de la maladie et du traitement)	O	O	O	O
Évaluer la situation et les conséquences des différentes alternatives possibles.	O	O	O	O
Pondérer les informations obtenues dans le contexte de ses propres valeurs et attitudes.	O	O	O	O
Se référer à sa propre biographie, à ses expériences et à son savoir intuitif.	O	O	O	O
Participer au processus de décision au niveau émotionnel.	O	O	O	O
Exprimer son propre choix.	O	O	O	O

Question 5:

Évaluez-vous la capacité de discernement d'un patient en fonction de la **gravité (potentielle) des conséquences** d'une décision médicale? En cas de conséquences lourdes, par exemple, les **capacités mentales** doivent-elles satisfaire à des **exigences** plus élevées?

- O La gravité des conséquences n'a **aucune importance** pour mon évaluation.
- O La gravité des conséquences n'a **que peu d'importance** pour mon évaluation.
- O La gravité des conséquences est **relativement importante** pour mon évaluation.
- O La gravité des conséquences est **très importante** pour mon évaluation**.**

- O Je ne peux pas répondre à cette question, car je n'ai jamais évalué moi-même la capacité de discernement d'un patient.

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Question 6:

Imaginez la situation suivante :

Un patient souffrant d'un cancer doit décider s'il veut ou non être traité par chimiothérapie. La probabilité de stopper le développement de la tumeur grâce à la chimiothérapie et d'éviter les récidives est de 70 %. Par contre, il est hautement probable que le renoncement à un tel traitement conduirait en quelques mois à la mort du patient. Il n'existe pas d'autres possibilités thérapeutiques pertinentes dans ce cas. La capacité de discernement du patient est sujette à caution et exige une évaluation précise.

Dans quel cas posez-vous des **exigences élevées aux capacités mentales** pour l'évaluation de la capacité de discernement?

- O Le patient se décide pour la chimiothérapie.
- O Le patient se décide contre la chimiothérapie (renoncement thérapeutique).
- O Dans les deux cas, mes exigences concernant les capacités mentales sont élevées.

Question 7:

Le patient du cas relaté dans la question 6 décide de renoncer à la chimiothérapie. A la place, il demande un **suicide médicalement assisté**.

Vous êtes consulté pour évaluer la capacité de discernement du patient.
Quelles exigences doivent être satisfaites pour que vous déclariez le patient capable de discernement?

(plusieurs réponses possibles)

- O Les mêmes exigences élevées aux capacités mentales qu'en cas de renoncement thérapeutique.
- O Des exigences plus élevées aux capacités mentales qu'en cas de renoncement thérapeutique.
- O Je dois être personnellement convaincu qu'un suicide assisté est la meilleure option à la disposition du patient.

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Question 8:

Imaginez la situation suivante :

Une patiente démente souffre d'une insuffisance rénale qui exige un changement de traitement médicamenteux (intervention 1). Toutefois, à ce moment-là, la capacité de discernement quant à un changement de médicament fait défaut et le médecin ordonne ce changement en accord avec les personnes habilitées à représenter la patiente. Lors de la même consultation, l'opération chirurgicale d'une tumeur maligne de la peau sur le nez doit être discutée (intervention 2).

Comment procéderiez-vous pour recueillir le consentement de la patiente pour l'intervention 2 ?

- O L'**in**capacité de discernement ayant déjà été établie pour l'intervention 1, je consulte également les proches pour décider de l'intervention 2.
- O S'agissant de deux interventions différentes, je réévalue séparément la capacité de discernement de la patiente pour l'intervention 2 et ne décide qu'ultérieurement si le consentement des proches est nécessaire pour procéder à l'intervention.

Question 9:

Dans quelle mesure tenez-vous compte des **facteurs** suivants lorsque vous évaluez la capacité de discernement de patients?

- O Je ne peux pas répondre à cette question, car je n'ai jamais évalué moi-même la capacité de discernement d'un patient.

	pas du tout	moyen-nement	assez	beaucoup
La relation thérapeutique	O	O	O	O
Le tableau psychopathologique	O	O	O	O
Le tableau somatique	O	O	O	O
Le contexte médical (par ex. l'urgence du traitement)	O	O	O	O
Ma propre échelle de valeurs	O	O	O	O
Le contexte social (par ex. l'étendue du soutien social des patients)	O	O	O	O
La complexité des options thérapeutiques (par ex. le déroulement du traitement, les avantages et inconvénients existants)	O	O	O	O
Les informations et déclarations des personnes proches du patient	O	O	O	O

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Question 10:

A quelle fréquence évaluez-vous plus précisément la capacité de discernement d'un patient?

	jamais	rarement	souvent	toujours	non évaluable (je ne traite pas tels patients)
Démence de type Alzheimer	O	O	O	O	O
Troubles cognitifs légers (mild cognitive impairment)	O	O	O	O	O
Dépression unipolaire	O	O	O	O	O
Patients hospitalisés en médecine interne	O	O	O	O	O
Schizophrénie	O	O	O	O	O
Gliome	O	O	O	O	O
Personnes âgées en bonne santé	O	O	O	O	O
Maladie de Parkinson	O	O	O	O	O
Patients en fin de vie	O	O	O	O	O
Difficultés d'apprentissage	O	O	O	O	O

Veuillez établir un classement des **trois** maladies le plus souvent associées à l'**in**capacité de discernement (indépendant de votre domaine):

1)

2)

3)

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Question 11:

Les **comportements** suivants des patients vous rendent-ils **attentifs** à la question de leur capacité de discernement?

	jamais	très rarement	dans la plupart des cas	toujours
Un patient n'est pas d'accord avec le diagnostic/le traitement médical prescrit.	O	O	O	O
Un patient prend des décisions difficilement compréhensibles (par ex. demande de suicide assisté en cas de maladie pouvant être soignée).	O	O	O	O
Un patient délègue toutes les décisions au médecin ou à une autre personne, parce qu'il ne se croit pas capable de prendre une décision juste.	O	O	O	O
Un patient représente un danger immédiat pour lui-même ou pour autrui (par ex. comportement suicidaire ou menace physique envers autrui).	O	O	O	O
Un patient est désespéré et consent immédiatement et sans réflexion critique à toutes les propositions de traitement.	O	O	O	O
Un patient se déclare indifférent à la décision.	O	O	O	O
Un patient change plusieurs fois d'avis quant à une option thérapeutique déterminée.	O	O	O	O

Question 12:

Dans votre pratique quotidienne, **à quelle fréquence** vous arrive-t-il de penser que la capacité de discernement d'un patient est **sujette à caution**?

- O jamais
- O rarement
- O souvent
- O toujours

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Question 13:

Lorsque la capacité de discernement d'un patient est sujette à caution, **de quelle manière** l'évaluez-vous?

(Veuillez donner und réponse pour chaque affirmation)

	jamais	rarement	souvent	toujours
J'évalue la capacité de discernement dans le cadre de la consultation habituelle (**évaluation implicite**).	O	O	O	O
Je réserve une place séparée à l'évaluation de la capacité de discernement pendant la consultation (**évaluation explicite**).	O	O	O	O
Je consulte des **collègues spécialisés**.	O	O	O	O

S'il ne vous arrive **jamais** d'évaluer **explicitement** la capacité de discernement, faites l'impasse sur les questions 14 à 16 et reportez-vous directement à la **question 17**.

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Question 14:

Parmi les méthodes suivantes, laquelle appliquez-vous lorsque vous évaluez **explicitement** la capacité de discernement?

(plusieurs réponses possibles)

O Entretien libre avec des questions ayant un lien avec la situation

O Entretien semi-standardisé avec, en partie, des questions fixées au préalable

Si oui, nom et source de l'entretien:

O Entretien standardisé avec des questions précises

Si oui, nom et source de l'entretien:

O Questionnaire ou test écrit

Si oui, nom et source de l'instrument:

O Test non écrit (par ex. images, cartes, test oral)

Si oui, nom et source de l'instrument:

O Aucune des méthodes citées

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Question 15:

Lorsque vous évaluez **explicitement** la capacité de discernement, **informez-vous le patient** que les prochaines questions concernent l'évaluation de sa capacité de discernement?

- O jamais
- O rarement
- O souvent
- O toujours

Question 16:

Si vous avez répondu par « rarement », « souvent » ou « toujours » à la question 15 :

Pourquoi informez-vous le patient qu'il s'agit de l'évaluation de sa capacité de discernement?

Comment annoncez-vous au patient qu'il s'agit de l'évaluation de sa capacité de discernement?

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Question 17:

Pensez aux expériences les plus difficiles que vous avez vécues dans le contexte de l'évaluation de la capacité de discernement.

Quels sont les aspects qui vous ont **le plus compliqué** la tâche?

(Veuillez indiquer un maximum de 4 alternatives)

- O La pesée des risques et de l'utilité dans l'évaluation finale.
- O Les cas, dans lesquels la capacité de discernement était limite (zone grise) qui ne sont ni explicitement capables de discernement, ni explicitement incapable de discernement.
- O Des situations éthiques très complexes.
- O Des désaccords entre les médecins traitants ou avec les soignants.
- O Des facteurs dépendant du patient (par ex. manque de coopération).
- O Une situation familiale chaotique ou conflictuelle.
- O La manque de clarté du contexte juridique.
- O Aucun des aspects cités.

- O Je ne peux pas répondre à cette question, car je n'ai jamais évalué moi-même la capacité de discernement d'un patient.

Question 18:

A quelle fréquence avez-vous connu les difficultés décrites dans la question 17 lorsque la capacité de discernement d'un patient était sujette à caution et exigeait une évaluation plus précise?

- O jamais
- O rarement
- O souvent
- O toujours

- O Je ne peux pas répondre à cette question, car je n'ai jamais évalué moi-même la capacité de discernement d'un patient.

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Question 19:

Dans votre quotidien clinique, laquelle des **interventions/stratégies** suivantes pouvez-vous utiliser pour **améliorer** la capacité de discernement de vos patients?

Je reporte l'évaluation de la capacité de discernement à un moment ultérieur, si à cet instant le patient semble en mauvaise forme.

- O Je considère cela comme important, mais ne peux le réaliser.
- O Je considère cela comme important, mais ne peux le réaliser que partiellement.
- O Je peux réaliser cela dans la plupart des cas.
- O Je considère que cette intervention/stratégie n'est pas importante.

J'adapte la manière de présenter l'information aux patients (par ex. avec des informations complémentaires écrites, des diagrammes et des illustrations, le recours à des traducteurs).

- O Je considère cela comme important, mais ne peux le réaliser.
- O Je considère cela comme important, mais ne peux le réaliser que partiellement.
- O Je peux réaliser cela dans la plupart des cas.
- O Je considère que cette intervention/stratégie n'est pas importante.

Je modifie la posologie des médicaments pouvant influencer les capacités mentales.

- O Je considère cela comme important, mais ne peux le réaliser.
- O Je considère cela comme important, mais ne peux le réaliser que partiellement.
- O Je peux réaliser cela dans la plupart des cas.
- O Je considère que cette intervention/stratégie n'est pas importante.

J'encourage les patients à discuter de la décision à prendre avec des personnes proches.

- O Je considère cela comme important, mais ne peux le réaliser.
- O Je considère cela comme important, mais ne peux le réaliser que partiellement.
- O Je peux réaliser cela dans la plupart des cas.
- O Je considère que cette intervention/stratégie n'est pas importante.

Je donne aux patients la possibilité d'être accompagnés par une personne proche.

- O Je considère cela comme important, mais ne peux le réaliser.
- O Je considère cela comme important, mais ne peux le réaliser que partiellement.
- O Je peux réaliser cela dans la plupart des cas.
- O Je considère que cette intervention/stratégie n'est pas importante.

Je veille à ce que l'entretien se déroule dans une atmosphère agréable et calme.

- O Je considère cela comme important, mais ne peux le réaliser.
- O Je considère cela comme important, mais ne peux le réaliser que partiellement.
- O Je peux réaliser cela dans la plupart des cas.
- O Je considère que cette intervention/stratégie n'est pas importante.

Je tiens compte et j'aborde les aspects psychiques, tels que les peurs et les tendances au déni des patients, ou je procède à une brève intervention psychothérapeutique.

- O Je considère cela comme important, mais ne peux le réaliser.
- O Je considère cela comme important, mais ne peux le réaliser que partiellement.
- O Je peux réaliser cela dans la plupart des cas.
- O Je considère que cette intervention/stratégie n'est pas importante.

Question 20:

Connaissez-vous les instruments d'évaluation cités ci-après et les utilisez-vous?

Mac Arthur Competence Assessment Tool (MacCAT)

- O Je n'ai jamais entendu parler de cet instrument.
- O J'ai entendu parler de cet instrument, mais ne le connais pas plus en détail.
- O Je connais cet instrument, mais ne l'ai jamais utilisé.
- O J'ai déjà utilisé cet instrument, mais ne l'utilise plus, car je le trouve inutile.
- O J'utilise régulièrement cet instrument.

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Aid to Capacity Evaluation (ACE)

- O Je n'ai jamais entendu parler de cet instrument.
- O J'ai entendu parler de cet instrument, mais ne le connais pas plus en détail.
- O Je connais cet instrument, mais ne l'ai jamais utilisé.
- O J'ai déjà utilisé cet instrument, mais ne l'utilise plus, car je le trouve inutile.
- O J'utilise régulièrement cet instrument.

Silberfeld's Competence Tool

- O Je n'ai jamais entendu parler de cet instrument.
- O J'ai entendu parler de cet instrument, mais ne le connais pas plus en détail.
- O Je connais cet instrument, mais ne l'ai jamais utilisé.
- O J'ai déjà utilisé cet instrument, mais ne l'utilise plus, car je le trouve inutile.
- O J'utilise régulièrement cet instrument.

Hopkins Competency Assessment Tool (HCAT)

- O Je n'ai jamais entendu parler de cet instrument.
- O J'ai entendu parler de cet instrument, mais ne le connais pas plus en détail.
- O Je connais cet instrument, mais ne l'ai jamais utilisé.
- O J'ai déjà utilisé cet instrument, mais ne l'utilise plus, car je le trouve inutile.
- O J'utilise régulièrement cet instrument.

Autres:

- O J'ai déjà utilisé cet instrument, mais ne l'utilise plus, car je le trouve inutile.
- O J'utilise régulièrement cet instrument.

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Question 21:

Quel autre type d'instrument d'évaluation de la capacité de discernement utiliseriez-vous dans votre pratique clinique?

(plusieurs réponses possibles)

- O Entretien semi-standardisé avec, en partie, des questions fixées au préalable
- O Entretien standardisé avec des questions précises
- O Questionnaire ou test écrit
- O Test non écrit
- O Aucun des instruments cités

Question 22:

Pensez-vous que des **directives officielles** (par ex. par l'ASSM) seraient utiles pour l'évaluation de la capacité de discernement?

- O Je trouverais cela tout à fait inutile.
- O Je trouverais cela assez inutile.
- O Je trouverais cela plutôt utile.
- O Je trouverais cela très utile.

Question 23:

Pensez-vous qu'il serait pertinent que l'évaluation systématique de la capacité de discernement soit abordée dans **la formation prégraduée, postgraduée et continue** de manière plus précise que celle dont vous-même avez pu bénéficier?

- O Je ne trouverais cela absolument pas pertinent.
- O Je trouverais cela peu pertinent.
- O Je trouverais cela plutôt pertinent.
- O Je trouverais cela très pertinent.

Merci beaucoup!